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**Patients' experience of osteoarthritis and total knee replacement**

# PATIENTS' EXPERIENCE OF OSTEOARTHRITIS AND TOTAL KNEE REPLACEMENT

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# Abstract

Osteoarthritis (OA) is a common and disabling condition, and an important health care challenge with major resource implications. Total knee replacement (TKR) is a widely used and effective intervention for the treatment of knee OA, as determined by quantitative research. However, studies of patient experience of OA and TKR are limited and the perspectives of patients are poorly understood. This thesis investigates the experience of OA and a TKR, from the patient's point of view.

In-depth interviews with 25 patients were conducted three months before their TKR and 10 were followed-up and interviewed again six months after their TKR. Data were analysed according to the methods of constant comparison.

OA was perceived as a chronic and debilitating condition that was a 'normal' and inevitable consequence of ageing. The decision to seek treatment centred on the perception that symptoms were sufficiently severe to warrant treatment, as well as accidental injury and social sanctioning. Informants experienced difficulty in articulating their expectations about the surgery and preferred to describe qualified hopes and fears rather than predictions about what might happen. It was only after the experience of the operation that informants were able to describe their expectations in the light of what actually occurred. Individuals struggled to understand their outcome and often described it in contradictory terms. They presented both a 'public' expression of a good outcome, and a 'private' expression of an outcome that reflected their discomfort with the symptoms they were still experiencing. These apparently contradictory accounts were consistent in the context of the informants' lives, and represented adaptation or accommodation to their changed health state. Previous assumptions that TKR is a highly effective procedure may need to be qualified by these findings. More sensitive assessments of outcome are needed to capture patients' experiences, which incorporate the process of reconceptualising outcome and take into account the context of the individual.

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# Author's declaration

I declare that the work in this dissertation was carried out in accordance with the Regulations of the University of Bristol. The work is original except where indicated by special reference in the text and no part of the dissertation has been submitted for any other degree. Any views expressed in the dissertation are those of the author and in no way represent those of the University of Bristol.

The dissertation has not been presented to any other University for examination either in the United Kingdom or overseas.

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# Introduction

This thesis explores the experiences of patients with osteoarthritis (OA) undergoing a total knee replacement (TKR). OA is a common and disabling condition that affects the joints and TKR is a widely used effective intervention that is considered to be effective in the relief of pain and disability. However, the perspectives of individuals with OA and their experience of undergoing a TKR are poorly understood and under-researched. The main objectives of the study are to understand how individuals manage their severe OA, their views and experiences of a TKR, and their assessment of its outcome.

Chapter one is divided into two sections. The first section provides an overview of OA. A definition of OA is presented and the common symptoms (pain, stiffness and disability) are described, followed by a summary of the epidemiology of OA. The second section details research concerned with the effectiveness of TKR as a treatment. Unmet need for TKR and its indications are also discussed.

The focus of Chapter two is on the sociology of chronic illness. Experiences of chronic illness are reviewed in terms of the following issues: the uncertainty of being ill, the stigma attached to illness, biographical work and narrative reconstruction, the meanings attached to illness and how it is constructed, its effects on managing regimens and the family, and the effects on the body. The literature on coping strategies used by individuals with chronic illnesses, with particular reference to OA, is reviewed.

Chapter three explores patient expectations of a treatment and its relationship to satisfaction. A description of the common outcome measures used in assessing OA and TKR are also presented.

The design of this research and its associated methods are presented in Chapter four. Given the exploratory nature of this thesis, a qualitative methodology was utilised. This chapter details the philosophical background to qualitative research. A detailed outline of the sampling and recruitment of patients is provided, along with a discussion about how the interviews were conducted. An account of the method of analysis is detailed, followed by an outline of the criteria used for evaluating qualitative research in this study.

Chapter five documents the socio-demographic characteristics of the informants, while the main findings of the empirical work are presented in Chapters six and seven. In

chapter six, perceptions of OA, its aetiology and the experience of pain and disability are described, along with the problems of symptom recognition. The emotional impact of OA on the informants and their families is presented, as well as their attitudes towards taking medications. A description of the process of being listed for surgery is described and indicates some of the triggers of the decision to seek help, and also hints at some of the factors related to GPs' decisions to refer and consultants' decisions to list for surgery. Chapter seven examines the informants' pre-operation expectations about the pending TKR and describes the experience of undergoing a TKR. Their perceptions of the TKR outcome are also presented.

The final chapter of this thesis discusses the empirical findings in the context of the existing literature. The experience of OA in the context of older age, and the informants' help-seeking behaviour and their views of referral and listing for surgery are discussed. The findings regarding the informants' expectations towards their TKR are discussed and the perceptions of the TKR outcome are also examined. A reflection on the methods used and the implications of this research are also presented.

# CHAPTER 1: OSTEOARTHRITIS AND TOTAL KNEE REPLACEMENT

## Introduction

Osteoarthritis (OA) is the most common condition to affect the joints[1]. It is a severe and disabling condition, and an important health care challenge with major resource implications[2-4]. Total knee replacement (TKR), a well-established procedure, aims to improve a patient's quality of life, by reducing the pain caused by OA, and by improving mobility and function[5-7]. The work described here explores the experience of OA and TKR, from the patients' point of view.

The first part of this chapter provides an overview of the epidemiology and clinical aspects of knee OA. Difficulties of definition and diagnosis are highlighted, and the risk factors that predispose people to knee OA are detailed. The second part describes the effectiveness of TKR as a treatment for OA. Unmet need, practice variation, and TKR indications are also discussed.

## What is Osteoarthritis?

Osteoarthritis was first differentiated from other forms of arthritis at the beginning of the 20th century, when with the advent of radiographs, pathologists and radiologists separated chronic arthritic conditions into two broad groups[8]. The 'atrophic' group, characterised by synovial inflammation with erosion of cartilage and bone, were often poly-articular and primarily affected young people. This group now includes the conditions known as rheumatoid arthritis (RA) and septic arthritis. The 'hypertrophic' group was characterised by new bone formation around the damaged joint (hypertrophy), along with cartilage destruction. It occurred in fewer joints, in older people and was associated with ageing and trauma. It was subsequently renamed OA, and encompassed a large and heterogeneous spectrum of idiopathic joint disorders[8].

There have been recent advances in the understanding of OA. For many years OA was seen as a degenerative 'wear and tear' condition; an inevitable consequence of ageing and excess use of joints, for which there was little prospect of treatment[9]. This notion, however, is slowly becoming obsolete and is now regarded as erroneous[10,11]. Current opinion regards OA as the result of active processes, many of which are reparative

rather than destructive in nature[12]. In fact, many of the overt radiographic and clinical features of OA are due to the attempted repair of the damaged joint, i.e. subchondral bone sclerosis, and osteophytes (outgrowths of bone around the joint margin)[8]. It has also been suggested that it is a phasic disease process, with episodes of change being interspersed with long periods of stability in which symptoms may improve[13]. Spontaneous 'healing' can occur, particularly at the hip joint[14]. This suggests that OA has a stepwise course and can stabilise for many years[15]. Another development in the study of knee OA is that the disorder is now thought to be one of the whole joint, involving the synovium, capsule and subchondral bone as opposed to just the cartilage[8]. OA is, therefore, now described as a dynamic, changing process, combining features of joint damage and repair and affecting all tissues of the synovial joint[16].

Although evidence for this new approach is extensive, old concepts of OA remain deeply entrenched throughout the medical community and the public domain. These outdated perceptions of OA are changing, but at a slow pace. As new research emerges, the descriptions of OA change, but as yet a single satisfactory definition of OA remains elusive[11]. Definitions are difficult because OA is largely the reaction pattern of a joint to a variety of forms of damage, disease or abnormal anatomy: not only are all aspects of the reaction of a joint to damage variable, the response is quite different at the various joint sites involved[14]. However, with any working definition, consideration of pathological, radiological and clinical components tends to be examined[1].

## Pathological definition

The main pathologic features of OA have been recognised for many decades, and include focal areas of damage to the articular cartilage, associated with marginal osteophyte formation and increased activity in the subchondral bone, resulting in sclerosis, cyst formation and attrition[15]. These features are thought to develop due to dysregulation of tissue turnover in the weight-bearing articular cartilage and subchondral bone[8]. Attempts at cartilage repair take the form of cell proliferation and the formation of disordered reparative cartilage[16]. OA is therefore biochemically mediated, but it is probably mechanically driven, its localisation depending on loading[8]. OA can also be thought of as being due to age-related loss of ability of the tissue to respond to normal forces (primary OA), or to an inability of normal tissue to respond to excess loading (secondary OA)[11].

## Radiological definition

Plain radiographs are widely used as the 'gold standard' in assessing and diagnosing OA[17]. The radiographic features include loss of joint space, osteophyte formation, subchondral sclerosis, cyst formation and abnormality of bone contour[18]. All these features are difficult to measure but purport to reflect the various pathological changes that occur as a result of OA. Although several radiographic grading systems have been proposed, most epidemiological studies have utilised the Empire Rheumatism Council system, first described over three decades ago by Kellgren and Lawrence[17], and accepted by the World Health Organisation (WHO) in 1961[19]. This system assigns one of five grades (0-4) to OA by comparing the index radiograph with reproductions in a radiographic atlas. The criteria for increasing severity of OA follow an assumed sequential appearance of osteophytes, joint space loss, sclerosis and cysts[17]. Table 1.1 illustrates the grading scheme.

*Table 1.1 Kellgren and Lawrence radiographic grading system[17]*

| Grade | Classification | Description |
|---|---|---|
| 0 | Normal | No features of OA |
| 1 | Doubtful | Minute osteophyte, doubtful significance |
| 2 | Minimal | Definite osteophyte, unimpaired joint space |
| 3 | Moderate | Moderate diminution of joint space |
| 4 | Severe | Joint space greatly impaired with sclerosis of subchondral bone |

Despite this system being a widely adopted method, several problems have been highlighted[20]. Inconsistencies in the descriptions of radiographic features of OA have led to studies being performed using criteria that are discordant. These are briefly described below.

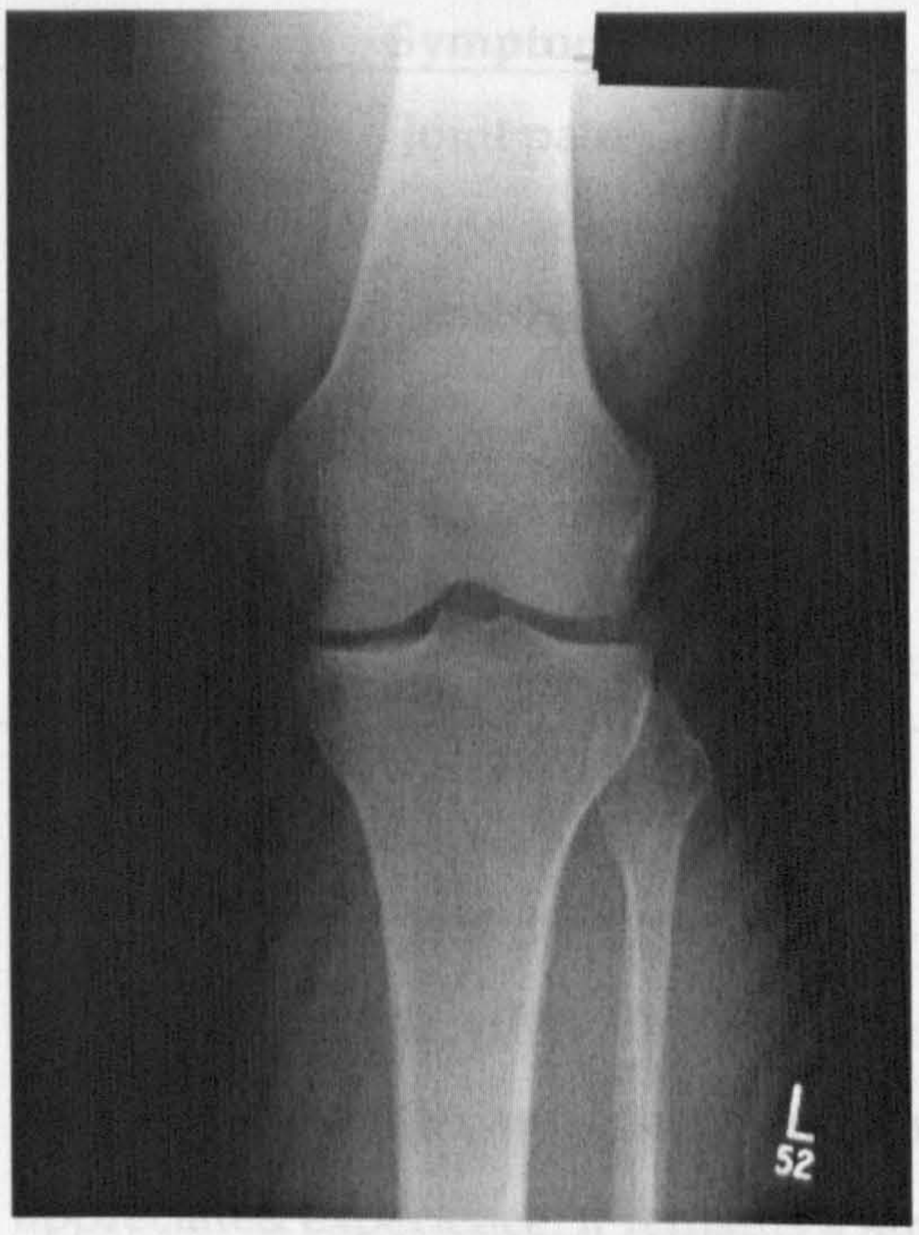
- Linearity between the grades cannot be assumed – the difference between grades 2 and 3 may be different from that between grades 3 and 4[14].
- Overall grading of a joint does not precisely differentiate changes in various compartments of the joint[14].
- The restriction to four grades makes it impossible to record subtle change or to account for worsening of a grade 4 joint[14].

- There is an overemphasis placed upon the osteophyte. Although an important feature of OA, osteophytes may occur independently. For example, in footballers, osteophytes may occur as a physiological response rather than a degenerative disease[21].
- The system only involves the antero-posterior view of the knee joint alone, so that no assessment can be made of the patello-femoral joint[22].
- Longitudinal studies illustrate that individuals with knee OA frequently report an improvement in their symptoms over time[13], although improvement in radiographic appearance is rare[23]. The radiograph, therefore, demonstrates changes that are the product of cumulative insults over time and is most appropriately regarded as an outcome rather than a process measure[15].
- A critical observation in the history of OA is the finding that radiographs and clinical presentations show poor correlation. Many joints with x-ray evidence of OA remain asymptomatic. Even grossly destroyed joints are sometimes symptom free[24].

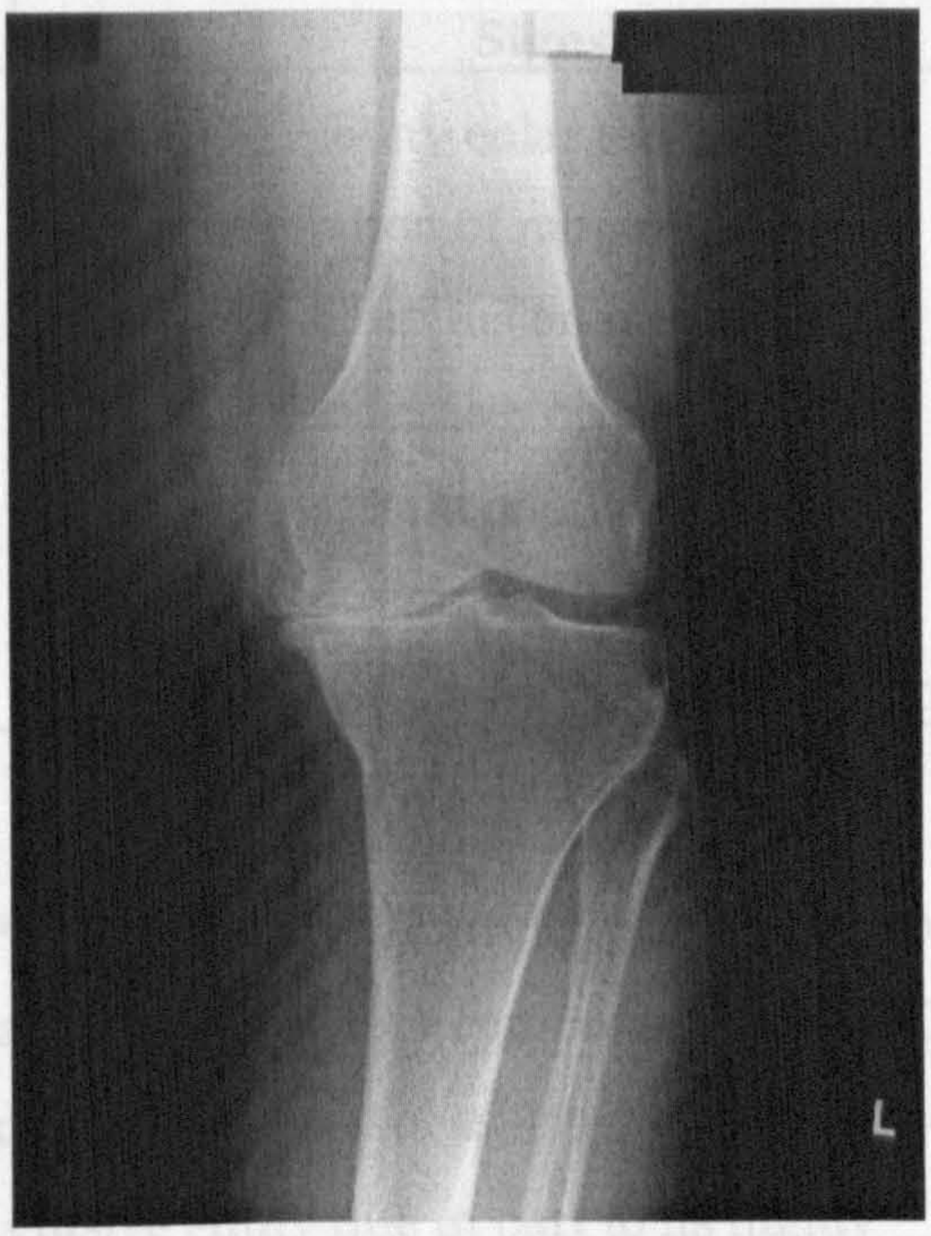
For these reasons, alternative descriptive approaches and ways of measuring individual parameters have been investigated[25,26]. Magnetic resonance imaging (MRI)[27] and scintigraphic[28] studies illustrate that OA is a condition characterised by widespread damage to soft tissue structures, as well as marked metabolic activity in the subchondral bone. In providing only crude images of bone, radiographs are a poor measure of the osteoarthritis process.

Despite the recognised deficiencies of radiographic evidence, it remains a cornerstone in the assessment of the progression of OA. The main reasons for using radiographs so extensively in OA is that they reflect, in part, the pathology; they are cheap, simple and can be used for epidemiology; and they are techniques which can be readily understood by clinicians[29]. Figure 1.1 illustrates two radiographs of the knee joint: one without and one with radiographic evidence of OA.

*Figure 1.1 Radiographs of a) knee joint without OA and b) knee joint with OA*




a) Normal radiograph of the knee.




b) Radiograph showing medial compartment joint space narrowing, marginal osteophytes and sclerosis of underlying bone.

## Clinical definition

OA can result in symptoms, such as pain and loss of function, causing disability, and changes in joints that can be detected on examination (signs). A classification schema for primary and secondary knee OA has been developed by the American College of Rheumatology (ACR), through a multi-centre study group[30]. The features said to have the most discriminatory power included age over 50, crepitus, bony enlargement, morning stiffness of less than 30 minutes and osteophytosis – the only radiographic predictor. While the ACR criteria were not intended to be used as diagnostic sets, it is probable that clinical practice reflects these guidelines[15]. The shortcomings of the criteria stated that the controls were not matched for age or sex, were younger than the patients with OA and included many patients with RA. Thus, at its simplest, the criteria have only been shown to perform well in the differentiation of OA from younger people with RA[31]. The clinical features of OA[11] are summarised in Table 1.2.

*Table 1.2 Symptoms and signs in patients with knee OA*[11]

| Symptoms | Signs |
|---|---|
| Joint pain | Bony enlargement |
| Morning stiffness | Limitation of range of motion |
| Gel phenomenon | Crepitus on motion |
| Buckling/instability | Tenderness on pressure |
| Immobility | Pain on motion |
| | Joint effusion |
| | Malalignment, joint deformity, or both |

***Pain***

Joint pain is the dominant symptom of OA[16], and the vast majority of people who come for treatment report this. The presence of pain is an obligatory component of the ACR criteria for knee OA assessment and classification[30]. In spite of it being a universally appreciated experience, it remains a largely elusive entity due in part to its highly subjective nature. It has variable severity and characteristics, but often occurs principally on joint usage and may be improved with rest[11]. It is generally localised to the affected joint, although referral to nearby areas can occur. Although it is initially intermittent, as the disease progresses, pain may become constant and increasingly severe and disabling. Nocturnal pain, interfering with sleep, is seen particularly in advanced OA and may be enervating. Longitudinal studies indicate great variation in pain intensity over time, with variations on a weekly as well as a daily cycle (pain being worse at the end of the day and end of the week)[32]. Duration, localisation and severity of pain are difficult to define, and no descriptions or definitions fully cover the subjective sufferings of patients: 'one person's pain is another's mere discomfort' (p.727[33]). However, some research has been conducted on the character of pain experienced by OA sufferers. Six different types of pain were identified: 1. pain of immobility, 2. pain of weight-bearing pressure, 3. pain on movement, 4. psychological factors, 5. pain of inflammation and 6. pain of trauma. An aching sensation associated with joint usage was considered the commonest form (type 2)[34]. This was mirrored in a more recent study[35].

The cause of pain remains obscure, although raised intra-osseous pressure[36], periarticular lesions[37] and inflammation can all contribute. Several observations strongly suggest that pain in patients with OA is not simply the result of structural

changes in the affected joint, but rather the outcome of a complex interplay between structural change, peripheral and central pain processing mechanisms, and subjective differences in what constitutes pain. These, in turn, may be influenced by age, gender and psychosocial factors[33].

*Disability*

Problems with joint movement is one of the hallmarks of OA[38]. The major determinants of disability include pain, stiffness, muscle weakness and joint instability, as well as a reduced range of movement[32]. Disability is often accompanied by pain that is at its worst at the end of the reduced range. The likely explanation is that chondrophytic and osteophytic lipping and remodelling of the joint, combined with the capsular thickening, prevents a free range of movement[32]. The informants' activities of daily living (ADLs) and the instrumental activities of daily living (IADLs) are often affected and can cause frustration and depression. ADLs include activities such as dressing, eating (self feeding), ambulating, transferring and hygiene, whereas IADLs include activities such as shopping, housekeeping, accounting, food preparation and transportation. For those with OA of the knee, extremes of flexion (squatting) or extension may be painful[39]. In addition, individuals may experience a sensation of insecurity or instability in the joints affected (the joint will 'give way').

*Stiffness*

Other symptoms reported by patients with knee OA include the sensation of stiffness[38]. Typically this "gelling" is much more severe after a period of inactivity, moving the joint through a range of movement, or it may be used to describe an ache or pain on movement[32,39]. Patients with early OA can recover quickly from the stiffness induced by inactivity during the day. In those with knee involvement, this stiffness typically subsides after only a few steps. With progression of the disease, however, the stiffness becomes more prolonged[39]. Patients tend to talk about having to 'work the joint in' after a rest period or first thing in the morning. In addition, patients with OA often complain of crepitus, a sensation of "cracking" or "popping" of the involved joint with movement. Deformities may occur due to OA of medial tibiofemoral compartment. For example, one knee may become larger than the other or angular deformities may occur, such as bowing of the knees (varus).

## Anatomy of knee

The knee is a complex joint, with three major compartments: the medial and lateral tibiofemoral joints and the patellofemoral joint[1]. OA usually occurs symmetrically and can affect each of these areas separately, or in any combination. The commonest combinations are isolated medial compartment, isolated patellofemoral compartment or medial plus patellofemoral disease[40]. The accompanying features of OA, for example, the extent of osteophytosis and subchondral bone changes, vary in their distribution[32]. Whereas the medial tibiofemoral compartment usually has the most articular cartilage loss, osteophytosis is more extensive in the lateral compartment. The loading of the knee may explain why some compartments are affected more often than others. During activity, when loads of 2-3 times body weight pass through the joint, the medial compartment takes the maximum, whilst in knee flexion the loading on the patellofemoral joint can reach 7-8 times that of body weight.

## Natural history of OA

The natural history of knee OA is not well described[14]. Disease evolution is slow; the onset of symptoms are usually gradual and the pain and stiffness of a joint may 'creep up' over months or years[1,41]. However, there is evidence that once established the condition can remain relatively stable, clinically and radiographically, for a period of several years[14]. Thus, due to this non-linear progression, the natural course of knee OA is difficult to predict. Four distinct types of outcome have been described: 'rapidly progressive', 'spontaneous healing', 'stabilisation' and 'slow progression'[14]. The stabilisation of OA appears to be a common observation in the knee joint, where signs and symptoms reach a point and then stop progressing, and can even regress (without resolving)[14]. It is unclear whether these different types of outcome represent distinct subsets of OA or are part of a continuum: they may overlap and interact. As a result of the spontaneous healing and stabilisation, patients with OA are able to adapt to the discomfort, reduced movement and stiffness, resulting in a relative improvement in quality of life. However, the progression of OA can result in chronic disabling symptoms. In the minority who come to surgery, the joint usually has gone into a fairly sudden phase of dominant joint destruction (sometimes after a phase of stability). Thus, there is usually a relatively short period of worsening, with severe symptoms occurring a couple of years prior to the operation[41]. This phasic disease process has an important

impact when assessing the process and outcome of OA: single time-point studies can be misleading[42].

## Epidemiology of knee osteoarthritis

Epidemiology is the study of the distribution of diseases over time and in populations. This section describes the epidemiology of knee OA.

### Prevalence

There tend to be two categories of patients presenting with knee OA[43]: younger people, often men, with isolated knee disease that may be related to a previous injury or operation[44]; and middle-aged and older people, often obese and predominantly female, who often have symmetrical OA of other joint sites, including the hands[45]. In the majority of cases the condition takes years to evolve. The recent WHO publication on the burden of disease reported that OA was one of the world's largest health care problems[46]. OA was predicted to become the fourth most important condition in women, and the eighth in men in developed countries, using calculations based on years lived with disability. However, estimating the prevalence of OA is difficult. With a few exceptions prevalence studies have focused on people with radiographic disease, many of whom are asymptomatic, and as stated above the factors differentiating symptomatic from asymptomatic radiographic disease are unknown. Furthermore, it should be noted that the majority of the radiographic prevalence estimates have obtained only tibiofemoral views and have, therefore, missed instances of lone patellofemoral OA[40]. Thus, an underestimation in respect to OA of the whole knee may be evident. This was further illustrated by the use of other methods of prevalence estimation, such as systematic autopsy studies which have indicated almost universal evidence of cartilage change in people aged over 65 years[47].

OA prevalence in all joints correlates strikingly with age, from negligible in those aged 25-34 years to 20-40% in those aged 75 years and older[48]. The prevalence of knee OA is higher in men than in women up to approximately 45 years of age, beyond which the reverse is true, with the increase considerably more dramatic in postmenopausal women. It is estimated that about 6% of adults over the age of 30 suffer from symptomatic knee OA, with rates rising with age[49]. By the age of 65 years the female: male ratio varies from 1.5:1 to 2:1[48].

## Incidence

Few studies on the incidence of knee OA have been reported[50]. In the Framingham Osteoarthritis Study, rates of incident disease were 1.7 times higher in women than in men and did not vary by age. Among women, approximately 2% per year developed incident radiographic disease, while 1% per year developed symptomatic knee osteoarthritis[51]. A recent North American population-based incidence study measured symptomatic OA among members of a health maintenance organisation[52]. The age- and sex-standardised incidence rate for knee OA was 240 per 100 000 person years. The incidence increased with age, and women had higher rates than men, especially after the age of 50. In women aged 70-89, the incidence of OA of the knee approached 1% per year. A levelling-off or decline occurred for both groups at around the age of 80. Studies conducted in the UK by the Royal College of General Practitioners in 1981/2 showed an annual incidence of symptomatic OA of 50/1000 in women and 29/1000 in men over 75 years old[53]. However, these figures are based on consultation rates and may be an underestimation of the true incidence of symptomatic OA.

## Economic burden

OA costs Britain millions of pounds annually[54]. It results in many days lost from work, puts more on the national drug bill than does any other arthritic disease, and is the most frequent reason for joint replacement surgery. The economic implications vary in different countries, depending on the amount of work loss, as well as the care provided, and in particular on the provision of hip and knee joint replacement (globally, some 80% of all joint replacements are done for OA of the hip or knee)[55]. It is likely to become an even bigger problem for health care systems with ageing populations, and increasing demands for good health amongst older people.

## Risk factors

Risk factors for knee OA can be divided into 'intrinsic' factors which are indicative of a general predisposition to OA, and 'extrinsic' factors which relate to a mechanical element[50]. These are illustrated in Table 1.3.

*Table 1.3 Factors associated with osteoarthritis*

| Intrinsic factors | Extrinsic factors |
|---|---|
| Age | Trauma |
| Sex | Joint shape abnormalities |
| Race/ethnicity | Occupational damage |
| Obesity | Previous joint surgery |
| Genetic predisposition | Physical activity |
| Reproductive factors | Local instability or hypermobility |
| Generalised hypermobility | |
| Other lifestyle factors (e.g. cigarette smoking) | |

## Intrinsic factors

### *Age*

OA is age-related although it is not clear what aspect of the ageing process predisposes to OA. In most cases, OA first becomes symptomatic in the 6th and 7th decades of life. The incidence rates suggest that this reaches a plateau in the seventh decade[11].

### *Sex and race*

When all joints are considered together, there appears to be little or no overall sex difference in the prevalence of mild OA. A female preponderance becomes more apparent, however, for severe grades of OA, in older age groups, and for OA of the hand and knee[48]. Knee and hand OA are common in Caucasian women whereas African women tend to develop knee disease only[56].

### *Obesity*

Population based studies of osteoarthritis have consistently shown that overweight persons are at higher risk of having knee OA than non-overweight controls[57]. Estimates of risk vary and depend to some degree on both the criteria for overweight and the definition of OA. The National Health and Nutrition Examination survey conducted throughout the USA, in 1971-1975, found that obese women (body mass index (BMI) greater than 30, yet ≤ 35) had almost four times the risk of OA as women whose BMI was under 25. For men in the same overweight category, the risk was increased 4.8-fold over men who were of normal weight[58]. These risk estimates are similar to those found in other studies. Weight loss appears to reduce the risk of development of knee OA and

improve symptoms in those with disease[51]. In the Framingham Study, it was reported that a weight loss of approximately 11 pounds in women of medium height was associated with a roughly 50% reduction in the risk of developing symptomatic knee OA[59]. Until recently, it was not clear whether obesity preceded (and perhaps caused) OA, or whether obesity resulted from the sedentary lifestyle of patients with OA. Studies now suggest that the former assertion is correct. Analysis of the Framingham epidemiological study in the USA has revealed that obesity predicted subsequent knee OA up to 30 years later[51]. The Health and Examination Survey (HANES) data has also shown that obesity is consistent in its association with both symptomatic and asymptomatic OA[60].

***Genetic predisposition***

The relative contribution of genetic and environmental factors to common forms of OA affecting the hands and knees remains unclear. A clear genetic influence was demonstrated using 500 unselected female twins aged 45-70 years who were screened radiologically for OA of the hands and knees[61]. The correlations of OA disease status were consistently twice as high in 130 pairs of identical compared to non-identical twins. The influence of genetic factors was estimated to be between 39% and 65%, independent of known environmental or demographic confounders. These results demonstrate that genetic predisposing factors may be very important, however, no single gene locus has yet been identified. Although mutations in the gene for type II collagen (COL2A) have been associated with early poly-articular OA, it is unlikely that there is a single gene for a structural component of cartilage that fully explains the genetic contribution of OA[62].

***Reproductive variables***

Sex hormones have long been thought to affect the occurrence of OA[63]. The marked female predominance of knee OA has led many commentators to suggest that it is hormonally mediated[64]. The disorder appears to increase in prevalence after the menopause in women, and OA has been associated with previous hysterectomy[65]. Cohort studies, such as the Framingham Osteoarthritis study examined prospectively the effects of oestrogen replacement therapy (ERT) on radiographic knee OA during 1983-1985. The results indicate that current use of ERT had a modest, but not statistically significant protective effect for radiographic OA, (odds ratio 0.71, 95% confidence interval 0.42, 1.20) among elderly white women[66]. However, case-control

studies evaluating current or past oestrogen use in women with and those without symptomatic OA have been inconsistent[67,68]. Thus the current evidence is at best suggestive of a protective effect of oestrogen on OA[63].

### *Generalised hypermobility*

The range of motion of any joint has a normal distribution in the population[1]. Hypermobility diminishes rapidly throughout childhood and then more slowly during later life. Marked premature OA has been reported in patients with generalised hypermobility[69]. However, the strength of the association with OA, as well as its precise mechanism, remains a subject for further study[1].

### *Other factors*

Associations have been suggested between knee OA and several medical conditions including: diabetes mellitus, hypertension, and hyperuricaemia[22]. It has also been suggested that OA may be influenced by certain social factors. There is conflicting evidence on the effects of smoking on OA. Previous studies have suggested that smoking might be mildly protective against the development of OA of the knee[70]. However, the Chingford study did not support this inverse association. In the small number of subjects with generalised OA (22 women) there was a non-significant 40% reduction of radiological OA in ever smokers (odds ratio 0.63, 95% confidence interval 0.24 to 1.68)[71].

## Extrinsic factors

### *Mechanical factors*

Mechanical factors leading to OA include previous surgery or trauma, abnormalities of joint shape, occupation-related use of the joint, and physical activity, such as elite sport.

### *Previous surgery/Trauma*

Major trauma is a common cause of knee OA[1]. Two specific types of injury are particularly strongly associated: anterior cruciate ligament damage and meniscal tears. Follow up studies of patients with cruciate rupture have reported cartilage loss, even in young patients[72]. For menisectomy, many studies have illustrated the surgical removal of the meniscus following knee injury represents a significant risk factor for radiographic tibiofemoral OA[73]. However, the interval between surgery and development of knee OA is often very long, and local factors may interact with this

predisposition. In addition, the majority of those who have had a menisectomy still have a good knee joint some 25 years later. Other types of major injury, particularly fracture, may also alter mechanical function and predispose to knee OA[1]. A prospective cohort study of 1321 former medical students demonstrated that adolescents and young adults with traumatic injury to the knee joint, as well as persons with knee and hip injuries incurred during middle age, are at substantially increased risk for OA at the same joint later in life[74].

***Joint shape abnormalities***

Abnormalities that lead to an alteration in the shape of a joint predispose to OA. It has been proposed that dysplasia of the femoral condyles alters the biomechanical stability of the knee joint and predisposes individuals to OA, but this is difficult to discern without special radiographic techniques[50].

***Occupational damage***

Occupational physical activity exemplifies stereotyped repetitive use of particular joints over long periods of time. Self-reported heavy physical activity has been found to be a major risk factor for incident symptomatic OA of the knee among participants in the Framingham Osteoarthritis Study[75]. The risk of osteoarthritis of the knee appears to be increased by some occupations. Knee OA has been shown to be more frequent among miners, longshoremen, concrete workers and shipyard workers, than among clerical or office staff[1]. Other studies suggest that different activities affect different sites in the knee joint. Significant increases in the risk of symptomatic knee OA were found among men and women who engaged in prolonged kneeling, prolonged squatting and who had jobs associated with high physical demands[76,77].

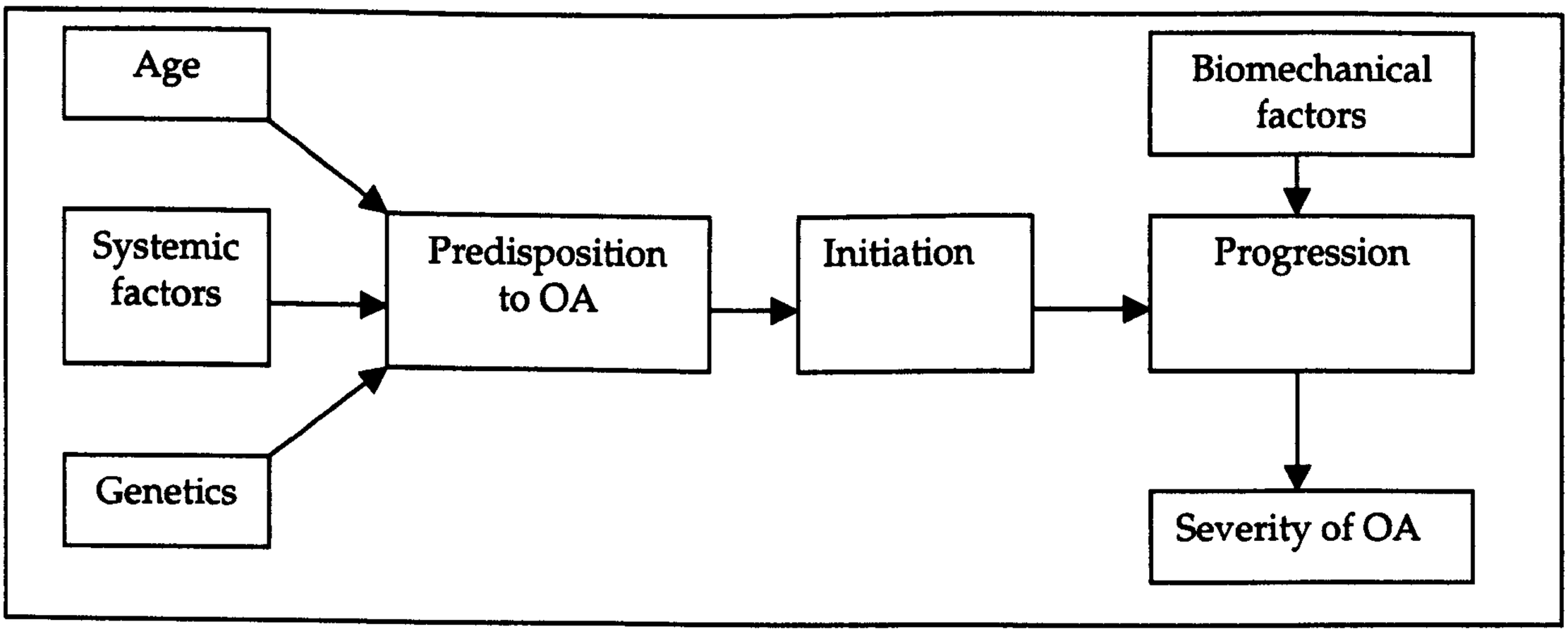
***Physical activity***

Participation in some sports has also been associated with an increased risk of knee OA[11]. However, recreational physical activity, such as jogging, does not appear to increase the risk of OA as long as the joints being subjected to repetitive stress are biomechanically normal[1]. Recent studies have suggested that it is elite athletes who are at an increased risk of knee OA in later life[78,79].

### Interaction of risk factors

An interaction of multiple risk factors may explain the predisposition to OA in most people[22]. OA is not a single disease entity and it does not have a single cause. The linking of intrinsic and extrinsic factors suggests that age, genes and systemic factors provide a background setting or predisposition for both the development and type of OA seen. Biomechanical factors, including joint anatomy, trauma and usage then probably dictate the site and severity of disease expression[8] (see Figure 1.2).

*Figure 1.2 A hypothesis on the interaction of biomechanical and biological factors in the predisposition of osteoarthritis[8]*




### Summary

Knee OA is a common disorder, with a major impact through consequent pain and disability. Simple historical definitions and concepts of OA have caused confusion in public and medical domains. Recent studies have helped to clarify the factors involved in OA and to support the contention that OA is treatable and can lead to improved quality of life. In clinical circles, this is slowly replacing the old perception that OA was merely an inevitable result of ageing. The next section will describe one of the major treatments for OA: total knee replacement, which is considered to be the final and irreversible step in the treatment of knee OA[80].

## Treatment of osteoarthritis

Due to the multifaceted nature of knee OA, a multidisciplinary approach to management is required[81]. The treatment strategies for OA are directed towards symptom control and the preservation and restoration of function[9]. Guidelines for management of knee OA[53,82] advocate a sequential approach, using simple measures

first, such as education and advice about exercise, footwear and weight reduction. The next step is the use of analgesics and physical therapy, followed by non-steroidal anti-inflammatory drugs (NSAIDs), intra-articular injections, and surgery, including TKR for the most severe cases. These treatments are variously provided through general practice, or via rheumatology, general medical and orthopaedic services[81]. The treatment should be individualised and based on the distribution and severity of joint involvement as well as the presence of co-morbid conditions.

## Total Knee Replacement

After the success of total hip replacements during the 1960s, a great variety of knee replacement prostheses were designed in the 1970s. Due to the lack of constraint on this development, many designs showed poor results, and went through a period of 'divergent evolution'[83]. As a result of this diversity, during the 1970s and early 1980s, total knee replacement was widely viewed as a relatively poor operation, particularly in comparison with hip replacement devices available at that time. Over the last three decades, however, improvements in surgical materials and techniques have greatly increased its effectiveness and have led to the current rapid increase in elective surgery in England, especially in adults over 65 years of age[84]. This has been labelled the TKR 'epidemic', with knee replacements now one of the most common major surgical procedures performed each year in the United Kingdom[83]. About 30,000 such procedures are carried out in England and Wales each year[85]. The rates of TKR/annum in the UK have been rising although there is still concern about unmet need[80,86,87]. As the average age of the population increases and patient expectations of health care rise, this promises to become more problematic in the future.

TKR surgery is considered to be an effective intervention which reduces knee pain and improves function[7,88-93]. A systematic review carried out in 1990 reported that over 60% of the TKRs were performed on patients with a diagnosis of knee OA, and stated that it was a safe and effective intervention[94]. Other studies have subsequently confirmed that TKR reduces knee pain and improves function in most of those operated on, therefore improving quality of life for patients with knee OA [88,89,91-93]. A meta-analysis of studies which measured patient outcomes using a global knee-rating scale, stated that 89.3% of patients reported to have a 'good' or 'excellent' outcome following tricompartmental knee replacements, at a mean follow up of 4.1 years. The range of the percentage of patients with 'good' or 'excellent' outcomes varied from 52% to 100% across all articles.

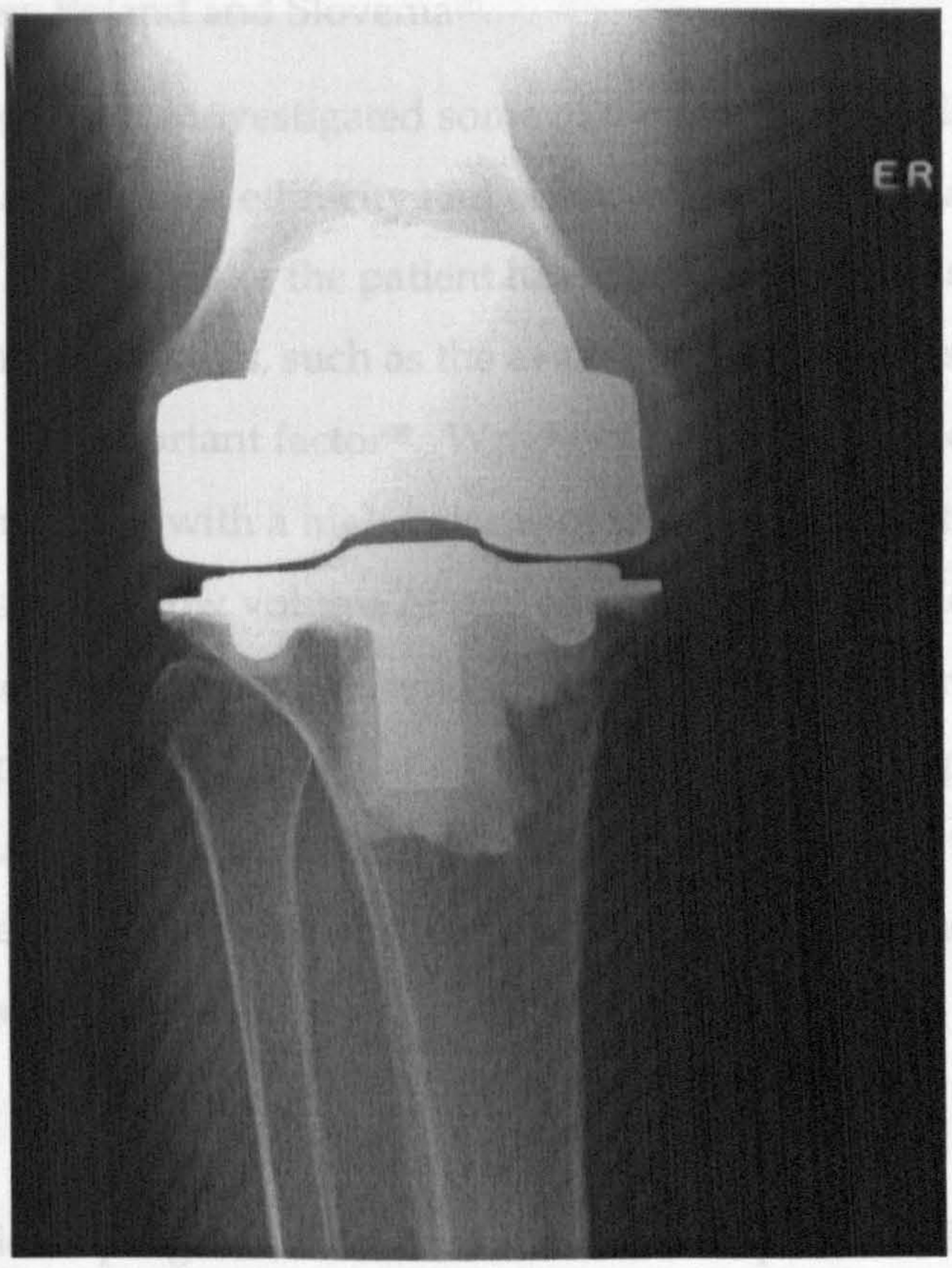
In addition, of the 26 studies that reported pain at follow-up, 75% of patients reported no pain[90]. Dieppe *et al*[80] have also reviewed the literature from 1990 to the present on interventions for knee OA. They found wide variations in the types of prosthesis and outcome measures used, making it difficult to compare the studies and come to any clear conclusion. Many of the studies, (mostly observational in methodology) used the survival of the prosthesis as the main or only outcome measure, rather than any patient centred outcomes. In spite of this, their overall conclusion supported the evidence to suggest that TKR is an effective treatment for knee OA. Figure 1.3 illustrates a radiograph of a replaced knee joint.

In addition to being considered an effective intervention, total joint replacement is also thought to be cost-effective[95]. Costs and benefits may differ markedly according to various patient characteristics, including age, severity of illness and underlying pathology. Few studies address such questions, although it appears that the cost-effectiveness of TKR is greatest amongst patients with the most severe disease and less effective for those with better preoperative health status[96]. Although evidence suggests that TKR is cost effective, there has been relatively little research on the topic. For example, there is no research stating whether it is more cost-effective if done early or late in the disease progress. Furthermore, little is also known about how TKR compares with non-surgical interventions.

## Need for TKR

As the numbers of TKRs continue to increase, it is anticipated that they will eventually match or exceed total hip replacement (THR) activity in England, which has now plateaued[81]. The Hospital Episode Statistics for 1991-1997 indicate that in the England and Wales, 50,000 total hip replacement are done per year, and some 2% of those over the age of 60 have prostheses[85]. UK knee replacement rates are currently lower (30,000/annum)[85], despite the fact that knee disease is about twice as common as hip disease[49]. In contrast, USA rates for knee replacements are now far higher than those for hip replacement[97]. It has been estimated that there is likely to be a 30% increase in need for all total joint replacements (TJR) in the next three decades, due to changing demography[98].

*Figure 1.3 Radiograph of a total knee replacement.*




Cemented, unconstrained total knee replacement

Despite the 'epidemic' of this intervention, TKR may be an under-utilised procedure resulting in a large unmet need in the population[80,86,87]. An epidemiological survey suggested that there was a high prevalence of people with severe knee disease who were not getting any medical intervention[87]. The USA Patient Outcomes Research Team (PORT) study also concluded that TKR is under-utilised[88]. This unmet need may be attributed to a lack of awareness of the potential benefits of TKR by general practitioners and patients, and scepticism due to adverse reports of surgical outcome of earlier outdated prostheses.

**Practice variation**

There is great variation of TKRs in practice[99]. Wide regional variations in operative rates exist in England and Wales, implying inequalities. In addition, research from the USA suggests that certain groups of people are less likely to get a TJR than others. For example, the elderly, the obese, and black people are less likely to have a TJR than middle-aged, middle class white people[80,88,100-103]. There are also similar discrepancies within European countries. Similar rates of use/head of population are seen in France,

Holland, Germany, Scandinavia, Switzerland and the UK, but lower rates in Ireland, Italy, Spain and Turkey, Poland and Slovenia[80].

Studies in North America have investigated some of the reasons for this variation[99,101,104]. The severity of joint damage, age, ethnicity and obesity were found to affect surgical decision-making[88,102]. Motivation of the patient has also been cited as important by surgeons[105]. Environmental factors, such as the availability of surgeons in the community were also an important factor[99]. Wright *et al's*[104] survey of orthopaedic surgeons found that surgeons with a high volume of knee replacement procedures were more likely than those with a low volume of procedures to perform knee replacement in patients who were under 55 years of age, who were obese, who could not walk more than a block without pain, who had pain at night, who had pain unresponsive to drug therapy or who had had septic knee arthritis more than 1 year earlier. Surgeons with high volumes of procedures were also less likely to perform knee replacements in patients who were employed.

## Prostheses

There has been significant progress in the evolution of concepts, techniques and design of TKRs during the past two decades, with the introduction of guide instruments and release procedures to ensure better alignment and stability. Virtually all TKRs attempt to duplicate the anatomy, motion and stability of the knee, with its ability to resist forces of normal daily activities[81]. A review of TKR prostheses indicated that there are 37 different TKRs, marketed by 14 companies[106]. At least 22% of the TKRs marketed had undergone major design modifications, while many others had seen smaller changes. The survey indicated that none of the new or modified TKRs had published short-term clinical data or long-term survival analysis before their introduction to the market[106]. This may be due to the lack of regulations for pre-introduction clinical trials. In addition, of the TKRs on the market, 54% did not possess any functional or survival results in peer-reviewed journals. All of these implants were introduced on to the UK market in the late 1980s and 1990s, suggesting that these new TKRs were introduced with little evidence of superior results. In the absence of follow-up studies, harm caused by such implants could go unnoticed. The most widely used implants at the moment in the UK are the Insall Burstein II (IB II), Kinemax, Press-Fit Condylar (PFC) and the Anatomic Graduated Component (AGC)[106].

Reliable and long-lasting prostheses are essential. Survival analysis of the life-span of prostheses suggests that 95% will last for 10 years and 85-90% for 15 years[107]. The results are equally good for OA and RA but questions have been raised about the reliability of these figures[83]. One fallacy in many survival studies is that those patients lost to follow-up had a similar chance of failure to those remaining in the study. This assumption may not be true. Murray (1997) found that patients with failed total joints often seek a second opinion and are referred to a sub-specialist for revision surgery[108]. "Worst case" analysis where all patients lost to follow-up are considered to have failed joints gives a more pessimistic (but possibly more realistic) view of joint survival. However, even with these more rigorous standards, many TKRs have excellent survival rates of 85% at 13 years[109]. The long term survival of knee replacements appears to be better than that of hip replacements[83]. However, the survival of the prostheses does not give any indication of the patient's experience of pain or disability.

## Indications for TKR

Another reason for variations in the rates of TKR is the lack of evidence-based indications for TKR in knee OA[80]. Waiting list management is becoming a major political issue and it is possible that standardised priority assessment will be introduced for common elective procedures[110]. The governing health body in the UK has indicated that length of time on a waiting list is an important factor, and has stated that no patient should wait over 18 months for their operation (Dobson, quoted in BMJ)[111]. Surgeons should allocate priority on the basis of greatest clinical need[111]. Searches were conducted on electronic literature databases to identify all articles related to the indications for TJR, in addition to hand searches of the relevant bibliographies. Ovid Medline (1965-3/01), Ovid Embase (1980-3/01) and BIDS Institute for Scientific Information (1981/01) were searched. Seven articles on the subject of criteria for the prioritisation of joint replacements were identified, two of which were confined to the hip

These criteria are consensus based rather than evidence based, and have come from health professionals, without input from patients with joint problems. Table 1.4 summarises these publications. A postal questionnaire survey sent to 328 orthopaedic surgeons in New York, USA[105], found that there was no absolute consensus among the orthopaedic surgeons. However most agreed that severe daily pain (particularly at rest), restricted walking distance, degree of joint space loss on radiographs and range of

*Table 1.4 Summary of the consensus based criteria for total joint replacement*

| Study | Population assessed | Method | Main outcomes |
|---|---|---|---|
| Naylor (1995, Canada)[112] | 4 orthopaedic surgeons, 2 rheumatologists, 2 GPs, 1 general physician, 1 epidemiologist, 1 physiotherapist | Delphi consensus technique - 120 case scenarios for surgical appropriateness were rated | Algorithms developed indicating that pain at rest, severity of functional impairment, problems with care giving and the perceived likelihood of improvement in function were the key determinants. |
| National Institutes of Health (1995)[100] | 13-member consensus panel representing orthopaedic surgery, rehabilitation and physical medicine, biomechanics, internal medicine | Consensus panel – answered predefined consensus questions, developed their conclusions based on the scientific evidence presented in open forum. | Consensus statement for THR only. Conclusion stated that THR is an option for nearly all patients with diseases of the hip that cause chronic discomfort and significant functional impairment. |
| Wright *et al* (1995, Canada)[104] | 234 orthopaedic surgeons | Survey | Patients' sex and race had no effect on the decision to operate. Patient characteristics that made the surgeons less likely to perform surgery included local active skin infection, major psychiatric disorder, alcohol or drug abuse, and high physical demands at work. Pain unresponsive to drug therapy made the surgeons more likely to perform knee replacement. |
| Mancuso (1996, USA)[105] | 328 orthopaedic surgeons | Postal questionnaire survey | No absolute consensus among the orthopaedic surgeons; however most agreed that severe daily pain (particularly at rest), restricted walking distance, degree of joint space loss on radiographs and range of motion were the key indications for TKR. Younger age, co-morbidity, technical difficulties and lack of motivation modified the decision against surgery, whereas the desire to be independent and return to work influenced the decision for surgery. |
| Hadorn (1997, New Zealand)[110] | 2 representative of the national health committee, 4 surgical services managers | Two stage Delphi technique | Numerical scoring scheme (New Zealand priority criteria scoring system) developed (with a maximum score of 100), based on severity of pain (40%), functional activity (20%), movement and deformity (20%), and other factors (20%), such as, effects on care or care-giving. |
| Quintana *et al* (2000, Spain)[113] | 9 orthopaedic surgeons | Two stage Delphi technique | Algorithm developed indicating that pain, functional limitation, previous non surgical treatment, surgical risk, age, and bone quality were the key criteria. |
| Harry *et al* (2000)[111] | New Zealand priority scoring system sent to 222 patients on TKR or THR waiting list | Postal survey | Three groups defined (consultant 'urgent' group, the GP 'urgent' group, the Department of Health 'urgent 18-month waiters').<br>The replacement of clinically urgent patients undergoing initiatives on time factors alone is therefore considered to be inappropriate, and not in the best interests of the patients as a whole. The authors conclude that the clinical prioritisation of patients can be facilitated by the use of a scoring system as they identify those in greatest clinical need, and is more useful than 'routine, soon and urgent' categories. |

motion were the key indications for TKR. Younger age, co-morbidity, technical difficulties and lack of motivation modified the decision against surgery, whereas the desire to be independent and return to work influenced the decision for surgery.

The Ontario criteria[112] used Delphi consensus techniques with a panel of health professionals, who rated 120 case scenarios for surgical appropriateness, to assess the indications for TJR. Algorithms were developed indicating that pain at rest, severity of functional impairment, problems with care giving and the perceived likelihood of improvement in function were the key determinants. The New Zealand priority setting criteria project[110] used a two stage Delphi process to derive surgical priorities for major joint replacement. A numerical scoring scheme was developed as a TKR indicator, (with a maximum score of 100), based on severity of pain (40%), functional activity (20%), movement and deformity (20%), and other factors (20%), such as effects on care or care-giving. Harry *et al*[111] examined the relationship between clinical priority and duration on the waiting list, by mailing a modified New Zealand priority criteria scoring system to 222 patients awaiting primary hip or knee arthroplasty. Three sub-groups of patients were defined, as follows:

- The consultant 'urgent' group – those who were listed as urgent on a clinical basis when seen initially in out-patients
- The GP 'urgent' group – those for whom the department had received a letter requesting expedition of surgical treatment
- Department of Health 'urgent 18-month waiters' – those who later received their operation in order to comply with the 18-month wait deadline.

There was no correlation between length of time on the waiting list and clinical score ($r=0.0$, 95% CI -0.14 to 0.14, $p<0.0001$). Thus, the authors argued that the replacement of clinically urgent patients undergoing initiatives on time factors alone was inappropriate, and not in the best interests of the patients as a whole. They stated that the clinical prioritisation of patients could be facilitated by the use of a scoring system as they identify those in greatest clinical need. This is more useful than the 'routine', 'soon' and 'urgent' categories[111].

Quintana *et al* developed and tested an algorithm using a modified Delphi panel judgement process criteria, which included pain, functional limitation, previous non-surgical treatment, surgical risk, age, and bone quality as the key criteria[113]. Wright *et al*'s[104] survey of orthopaedic surgeons found certain patient characteristics affected their

decision to perform knee replacement surgery. Patient characteristics that made the surgeons less likely to perform surgery included local active skin infection, major psychiatric disorder, alcohol or drug abuse, and high physical demands at work. Pain unresponsive to drug therapy made the surgeons more likely to perform knee replacement. Patients' sex and race had no effect on the decision to operate. Other publications indicate that orthopaedic surgeons regard pain severity as the main criterion for operating[104], and the mantra *'cannot walk, cannot work or cannot sleep'* is often quoted as the main indications for joint replacement[114]. This is also reflected by the main patient-related outcome measures in use in orthopaedic surgery, such as the American Knee Society Score[115], which identifies pain, physical functioning and joint damage.

As stated earlier, all these consensus decisions were based on health care professionals, mostly orthopaedic surgeons. Research does not seem to have considered the patients' perspectives as to what factors might be prioritised. A recent article attempted to delineate the factors most likely to determine the utilisation of TKRs for OA[80]. Three decisions were identified as the key for TKR utilisation: patients' decision to seek help from the medical profession; the decision of the medical 'gatekeeper' to refer the patient to an orthopaedic surgeon; and the decision of the surgeon to carry out a TKR on the patient.

## Summary

OA can become a chronic condition, meaning it can occur over a long period of time. It has a major impact on function, productivity, and quality of life. It is also one of the most expensive and debilitating rheumatic diseases. Clinical features can include pain in the involved joint, stiffness after periods of immobility, enlargement of the joint, joint instability, limitation of motion, crepitus, and functional impairment. It can cause extreme pain, stiffness and immobility. TKR is a successful and valuable intervention for the treatment of knee OA, resulting in major improvements in pain, function and quality of life, for many patients. However, as described above, there are a number of problems associated with knee surgery, including the lack of clear indications, variations and inequities in use, and possible under-utilisation. In addition, there is no research as to what it is like to undergo a TKR from a patient's point of view and what outcome of TKR means to patients. An understanding of the experience and views of people undergoing this operation could provide information about who benefits most from TJR. In the next chapter, the sociological literature relating to the experience of knee OA as a chronic illness will be described.

# CHAPTER 2: LIVING AND COPING WITH A CHRONIC ILLNESS

## Introduction

As stated in Chapter one, OA has in the past, been regarded as an inevitable 'wear and tear' condition. This has consequently led to negative approaches to both research and treatment[10]. The experience of those living and coping with OA has also received relatively limited research in the sociological literature. In contrast, there has been a great deal of research concerned with the experience of those with RA[116-122], possibly due to its more 'fascinating immunopathology and management problems'(p.262[16]). Nevertheless, OA is a chronic illness characterised by pain, stiffness and disability, and can cause considerable disruption to an individual's life. The procedures performed to treat OA (for example, TKR), involve major invasive surgery, but have, as yet, not been the focus of sociological research.

This chapter reviews the generic literature on chronic illness. There are several recurring themes in the literature: uncertainty; stigma; biographical work and narrative reconstruction; sociology of the body; managing regimens; information, awareness and sharing; family relations; and coping mechanisms[123-125]. These themes are discussed with particular reference to OA.

## Uncertainty

Sociological studies have demonstrated that many chronic illnesses are characterised by uncertainty[117,120,122,126-129]. Several types of uncertainty have been identified which can begin when the individual first notices that 'something is wrong', and can continue throughout the entire course of the illness[130].

### *Symptom uncertainty*

The first type of uncertainty is when the individual is unable to find an acceptable explanation for abnormal symptoms[123]. For many chronic illnesses, it is often difficult to make sense of symptoms and to contain them within acceptable boundaries. For example, the first symptoms in RA may overlap with a range of normal problems, causing difficulties in early recognition of signs and symptoms[117]. In other conditions onset might be more dramatic and sudden. For example, Scambler (1990) in his study

on epilepsy, stated that symptoms appear frighteningly 'out of the blue'. As a result of this changed situation, the individual has to find ways to deal with their illness[131]. When the onset of a chronic illness is gradual, and focussed within a particular joint (as in OA), symptoms are often attributed to something ordinary in the person's life[132]. However, the transition from trivial symptoms to a persistent problem can have an impact on an individual, as there is great uncertainty about the future[133].

Several studies indicate that individuals tend to treat the symptoms of OA as a normal consequence of ageing[134-137]. However, this view has been shown to differ according to social class. Elder in the 1970's interviewed 160 middle-aged Americans from five different social strata, who had specific symptoms of OA[134]. She found that respondents in higher class positions were more likely to attribute their OA to ageing, heredity, or to declare ignorance of the cause. In contrast, those in lower class positions were more likely to attribute their OA to exposure to the elements (cold, water, weather) and working conditions. These respondents were also more likely to blame themselves for their symptoms, which may reflect their belief that the failure to protect themselves from the elements caused the OA. In another US study, Kee (1998) interviewed 20 individuals with OA, and found the opposite: less advantaged respondents attributed OA to ageing more often than the more advantaged respondents[135]. Despite the discrepancies between the different social classes, OA is generally regarded as normal in older age. This has also been demonstrated by more generic qualitative work on lay views of health and illness[136,137]. Thus, because OA is viewed as an inevitable consequence of ageing, the experience of onset and symptoms may not be uncertain or disruptive. However, a recent qualitative paper showed that although older people portray their OA symptoms as a normal and integral part of their biography, they also describe the highly disruptive impact of symptoms on their daily lives[138].

Uncertainty about recognising symptoms may affect a person's decision to seek medical help[139]. Knee pain is generally thought to be a part of everyday experience and may be considered as not being symptomatic of any disease: this may delay medical help-seeking[140]. It has also been reported that people with knee OA who do not seek help may have developed coping strategies in that they do not 'catastrophise' their pain in the same way as those who do seek help[141]. Furthermore, the view of OA as an inevitable part of ageing may mean that symptoms are ignored or thought to be uncontrollable as they are thought of as 'normal'[80]. This has been demonstrated in an

interview survey of 203 individuals (aged 77 years and over): the acceptance of physical symptoms as a normal consequence of old age hindered consultation with their doctor[142]. Similarly, Morgan *et al* (1997) assessed 110 older individuals using a supervised questionnaire. They found that the informants considered locomotor problems to be normal for their age, and were therefore less inclined to disturb their GP[143].

Certain 'triggers' have been shown to affect the decision to seek medical help[144,145]. For example, the occurrences of an interpersonal crisis (a death in the family) or perceived interference with social and personal relations are more likely to trigger action. Thus, the severity of the condition, or extent of the handicap often dictates help-seeking behaviour[80]. 'Sanctioning' may also affect help-seeking behaviour. For example, it is usual for the individual to first discuss the uncertain signs and symptoms with significant others, such as friends, family or neighbours[146,147]. This is a process of exploring whether others view their symptoms as worthy for medical care. Sanctioning may also occur when an employer applies pressure on the symptomatic individual to seek help, if their symptoms are disrupting their work. The persistence of symptoms beyond a set deadline or time limit may also influence seeking medical advice[144].

***Medical uncertainty***

A second type of uncertainty is medical uncertainty. The time between the first experience of symptoms and eventual diagnosis may be lengthy[123]. This can be a period of distress as individuals are unable to find an acceptable explanation for abnormal symptoms. For example, individuals with neurological diseases are often thought of as having 'psychological diseases' before an accurate diagnosis is made[127]. In addition, patients with chronic disease can be difficult for a medical practitioner to manage. There may be instances where the doctor may not know what the problem is or may not be able to make a reliable diagnosis, thus creating anxiety for the individual[116]. This may place the patient in a vulnerable position: they view themselves as having an *illness* but are not medically defined as such, and so do not have the legitimate label of having a diagnosis of *disease*. Without a definite diagnosis, being labelled a 'malingerer' or a 'hypochondriac' is not uncommon amongst people in the early stages of chronic illnesses[129]. In many instances, the initial response of the doctor is to prefer less threatening diagnoses for non-specific symptoms. Whilst this 'normalisation' by the

doctor is initially welcomed, as symptoms persist, the failure to find an acceptable explanation may become distressing[148].

In many chronic illnesses, the prognosis is often uncertain, and only the evolving course of the disease can provide enough information to make a reasonable estimate of what is going to happen and when[149]. In a study of individuals with RA, Weiner (1975) noted how the stock response of many doctors and nurses at that time – 'You're going to have to learn to live with it' – was of little help to someone confronting the personal experience of living with an unstable, unpredictable chronic disease[120]. Donovan's (2000) qualitative study of 35 individuals (who had inflammatory arthropathies or other rheumatological complaints), emphasised the importance of providing reassurance in the medical consultation[118]. Tape-recordings of patient interviews approximately a week before and one week after their appointment were conducted, along with the information exchange between patient and consultant at the hospital appointment. It was found that the typical methods of communicating reassurance, such as emphasising the minor or early stage of the disease, were not necessarily interpreted as comforting by patients[118]. Due to the fact that the informants' symptoms had already affected their everyday life, this emphasis on the mildness/early stage of their disease raised the vision of future pain and disability. Thus, the doctor's well intentioned efforts to reassure the patient had the opposite effect. Although this work was based on individuals with RA, individuals with OA may experience a similar situation.

***Diagnosis uncertainty***

A third type of uncertainty may come from the diagnosis itself. The process of official diagnosis and labelling may be regarded with relief as threatening events are brought under control, and it brings to an end a long process of 'unknowing'[133]. Alternatively more information may reveal what was not known: diagnoses offer reassurance at a time of apprehension and anxiety but also open up concerns about the long-term nature of the disorder[126]. Uncertainty after diagnosis relates to the future course of the disease. For example, questions such as, 'what will happen to me' 'how quickly will it progress' or 'will it be painful' are often raised[132]. Scambler introduced the concept of 'negotiation' to explain the reaction of most individuals to being diagnosed as having epilepsy[131]. He stated that the majority of patients were upset by a diagnosis that they had not expected. As a result, they set about discussing with family or friends the different ways in which the doctor might be mistaken or exaggerating. The apparent

failure of doctors to explain the causes of epilepsy was used as a basis to renegotiate the diagnosis. On a similar issue, individuals with arthritis (especially RA, because of its lack of known aetiology) may doubt the original diagnosis when they experience a 'good' day, only to be 'knocked back again' when the symptoms reappear[133]. The diagnosis uncertainty may be less of an issue for those individuals with OA, as it is, in general accepted as part of the ageing process. However, it is not only the elderly who experience OA: relatively young individuals who experience knee OA due to a sports injury will probably not view themselves as old, and this may cause some uncertainty.

***Trajectory uncertainty***

A fourth type of uncertainty is trajectory uncertainty. Many illnesses are inherently episodic in nature; acute flare-ups are followed by apparent remissions. The location and severity of pain varies day to day and may change even during the day (as in OA). For example, the uncertainty of living with RA makes both short - and long-term planning impossible and living arrangements often have to be rearranged[129]. In addition, the person with RA is faced with having to accept the unpredictability of his or her body and its dictates, whilst continuing to respond to the demands and requirements of daily life[130]. In OA, the long-term course tends to be more predictable than uncertain. As stated in Chapter one, there is often a gradual deterioration over a long period of time, although in some cases people appear to improve or deteriorate rapidly[13,86]. However, in the short-term, individuals with OA have to overcome the pain, stiffness and immobility of their condition on a daily basis. Insecurity or instability in the joints affected can occur at any time.

***Uncertainty of going into hospital***

A fifth type of uncertainty, which has been relatively neglected, is the uncertainty of going into the hospital for an operation. Strauss *et al* indicated that 'chronic illness trajectories flow from home residence into and through hospitals, and out again back to the home' (p.142[149]). William's (1993) study on respiratory disease showed that patients often approach hospitals with a mixture of relief and apprehension. Relief may be evident because they are often admitted when they are most ill and welcome the chance of respite and alleviation of symptoms. However, going into hospital may also cause apprehension especially when treatment fails to help adaptation[150].

Commentators have stated that there are problems with the hospital organisation and its relationship to chronic illness[149,151]. They argued that hospitals are increasingly becoming 'technologised' with the advancement of specialised machines, drugs and surgery. In addition, the care, the staff skills and the organisation of the hospital are becoming more complex, affecting the work that goes into giving care to patients as well as on the experiences that people have while hospitalised. The picture of the hospital patient as an acutely sick person, (passive and acquiescent) being treated by an active physician, as in the classic 'sick role'[152], is not an accurate depiction of chronically ill persons[149]. This is because many of these individuals have obtained vast amounts of knowledge of their condition and are skilled in managing their symptoms. Stacy argued that research must attempt to find ways of according lay knowledge equal worth to other forms of knowledge based on the assumption that lay people and patients are a major source of expertise and skills and are knowledgeable about the management of health and illness[151]. Strauss *et al* state that while in hospital, individuals with chronic diseases do various types of 'work' which is dependent on their beliefs, context and biographical features of their illness[149]. Thus, rather than being considered a consumer of health care, the patient should be considered a partner in the health-care team, and a producer as much as a consumer of health care[151].

## Stigma

Goffman's (1963) classic work on "stigma" and how individuals deal with the "stigma" of disability is particularly important to chronic illness and OA[153]. Individuals with chronic disease are often referred to by the medical label that a doctor has applied to them: a person's individuality and uniqueness may be subsumed beneath a term such as 'arthritic' or 'asthmatic'[154]. Individuals may feel shame if they are unable to fulfil tasks normally associated with their social role, or perform the usual activities of self-care. Thus, disability can cause major disruption to an individual's life and expose threats to self-identity and a loss of self-control; it can become the ground for a "spoiled" identity, that is, one of a lesser social value. Goffman defined stigma as:

> *"an attribute that is deeply discrediting. Stigma can arise of [one] possessing an attribute that makes [that person] different from others... and of a less desirable kind... [S/he] is thus reduced in our minds from a whole and usual person to a tainted, discounted one." (p.12–13[153])*

The nature of stigma can be distinguished into 'discredited' or 'discreditable' groups[153]. Those individuals with overtly visible symptoms are said to be 'discredited' and must

temper the tension their stigma causes in order to successfully interact with others. The emphasis on 'idealised normative identity and conduct', limits the ability of the 'discredited' individual to achieve full acceptance by the population that s/he is forced to integrate with. Those with less visible symptoms are said to have a 'discreditable' stigma and are forced to limit the access of others to information about the stigma, or assume the character of a discredited individual. For the 'discreditable' individual, such as those with OA, the experience of stigma has been shown to lead to 'withdrawal', 'covering' or 'passing' signs of their differences; they attempt to present themselves as normal by concealing information about themselves[153]. 'Passing' involves deliberate concealment of the disability, while 'covering' involves subtle strategies to keep the stigma from being noticed in particular situations. Those who conceal 'discrediting' or 'dishonouring' illnesses, have to carry the burden of anxiety that their concealment may be discovered. At the very least, that discovery may be embarrassing, but it also could be humiliating or bring about unemployment[149]. Goffman argued that stigmatised individuals organised their self-image defensively, that is, they tried to appear normal, mask their stigma and renegotiate their identity in each new situation so as to avoid being exposed. Studies of stigma related to epilepsy also draw a distinction between 'felt' and 'enacted' stigma[131]. 'Felt' stigma refers to the shame associated with the illness and the fear of being discriminated against on account of the illness: 'enacted' stigma refers to actual experiences of discrimination. 'Felt' stigma can be more disruptive on the individual's life than 'enacted' stigma, as the fear of public attitudes may be so great that individuals may avoid disclosing their diagnosis.

Wiener's study of 21 individuals with RA also showed how patients attempted to 'pass for normal' and disguised their arthritic symptoms ('cover up'), to avoid negative or stigmatising responses[120]. 'Keeping up' with what the individuals perceived to be normal activities was also an aspect of living with chronic illness and was an attempt to 'prove a capacity, to deny incapacity, or to recapture a former identity' (p.291[120]). Many individuals 'kept up' successfully but then suffered afterwards. These strategies were useful for the individuals with arthritis to remain normal but when they could not manage, it was harder for them to justify inaction to others. They could not legitimise their abnormality because sometimes they were normal, and other times, although hurting they would 'cover' or attempt to 'keep' up. Weiner also described the process of 'pacing' whereby the individual identified the activities that they could still achieve. For example, the individuals in Weiner's study used pain-free days to do as much as

possible to make up for days of forced inactivity. This strategy was important as these were the activities that allowed the individuals to view themselves as 'normal'. The idea of concealment was also highlighted in Williams and Barlow's study of RA patients[155]. They found that clothing was chosen and worn to mask bodily change, to reduce feelings of self-consciousness, and to maintain an appearance similar to that of same-aged peers. The patients were also reluctant to disclose their feelings about the changes to their body as they wanted to maintain some degree of privacy, as well as to shield family and friends from their inner pain and suffering.

Little work has been focussed on the stigma of having OA. However, the stereotype of an older person who must inevitably suffer because of reduced mobility, health and status is widely portrayed. For example, the road sign of the two persons bent over a walking stick as a indication of elderly people crossing the road, epitomises this image[80]. Thus, individuals with OA may feel stigmatised when they use walking sticks, walk with a limp or withdraw from their usual activities.

## Biographical work and narrative reconstruction

Several researchers have studied the effects of chronic illness on the self and self-identity[116,122,156,157]. Individuals with chronic illness have constantly to deal with new situations resulting from their condition. Bury (1982) refers to the impact of chronic illness as a 'biographical disruption' and calls into question both past and future. The onset and persistence of symptoms disrupt the normal flow of everyday life, and the disabling effects of chronic illness become problematic, both physically and mentally. For example, Bury's qualitative study of the emerging impact of RA on 30 relatively young women and men, noted that much of the distress relating to diagnosis was owing to the image of arthritis as an 'old person's' disease and the 'premature ageing'[158] that this implied. He identified three aspects of biographical disruption[116], p169-70:

> *"First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of commonsense boundaries [...] Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental rethinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources in facing an altered situation."*

Treating chronic illness as a disruptive event brings into focus the meaning of the illness within a social context as well as the available resources to manage the burden of the

illness. Bury identified two types of 'meaning' in chronic illness: the *consequence* and the *significance* it has on the individual[117]. The *consequence* of illness referred to the disruptive changes which chronic illness creates: for example, activity restriction (disability) and social disadvantage (handicap). The *significance* of chronic illness referred to the different connotations that conditions carry, which may have a profound influence on how individuals perceive themselves, and how they think others view them. By introducing the idea of significance, Bury asked questions about the person's *explanation* given for their illness and its *legitimacy* in their life. The term legitimation referred to the attempts made 'by the person to establish an acceptable place for the condition within an altered daily life and within the web of social relationships in which the person's life may be enmeshed' (p.125[159]). This would help the individual not only to gain control over their condition but also establish a 'proper sense of perspective about the condition, and re-establish credibility in the face of the assault on self-hood' (p.456[124]).

Williams (1984) has argued that the way to sustain a sense of the life-course is through narrative: the story that weaves together the variety of events and experiences that make life. He found that individuals with RA tried to establish a form of 'narrative reconstruction' of events leading up to and through the illness[122]. Thus, the person's biography was reorganised in order to account for the onset of illness so that it makes sense in terms of the person's life story. This was formed to reduce its threat to everyday meanings that had prevailed from the illness, and the need to piece together into a meaningful account the story of their illness[121]. Thus, the reconstructed narrative sought to answer questions such as 'why me?' and 'why now?' not only in terms of 'what caused me to become ill?', but also 'to what end or purpose have I become ill?'[160].

Although the concept of 'biographical disruption' has provided both an implicit and explicit framework for much of the sociological research into chronic illness experience, it has, in recent years, been extended and alternatives have been proposed. A criticism of biographical disruption is its exclusive focus on an adult-centred model of illness[161]. It is, thus, reliant on the assumption that an individual's life has been untouched by crises or struggle before an illness occurs. As such, it neglects people who have had chronic illnesses from birth or early childhood, which must be integral to an individual's biography. A recent paper challenged the theory of biographical disruption, exploring its applicability to asymptomatic HIV-positive men, infected either through homosexual

relations or medical treatment for haemophilia[162]. They reported that although the diagnosis disrupted these men's lives, it had the effect of *reinforcing* aspects of their biography. The interviewees reinterpreted and reconstructed their individual and collective pasts to the current situation. For example, some of the men with haemophilia felt that HIV infection was a continuation of their biography because they were used to organising their lives around their illness. Similarly, while the HIV infection was individually experienced as disruptive by many of the gay men, for these men *collectively*, it represented a continuation of the political activism which many of them had been involved in, as gay men. Thus, rather than experience a 'biographical disruption' the men recomposed a sense of identity and attempted to give continuity to their biographies, reinforcing aspects of their collective biography. The authors of this paper raised the importance of contextualising illness, both within the life of the individual and the collective to which they belong[162].

Another criticism of 'biographical disruption' is that it does not take into account particular class- and age-related connotations, or gender and ethnic dimensions. For example, Cornwell highlighted the variety of so-called 'normal' crises among many people living in the East End of London[163]. She showed that much illness is greeted with cheerful stoicism and pragmatism. Similarly, Pound *et al* provided valuable insights into the nature and experience of stroke among elderly working-class people[164]. They illustrated how people perceived illness and disability as a normal part of ageing rather than as a profound disruption to their lives. Age was a key factor mediating between the experience and response to chronic illness. Pound *et al* stated that by the time people were into their 70s, their experiences 'may have equipped them with considerable skills which enable them to deal with crises and successfully adapt to new situations such as chronic illness' (p. 502[164]). This may have important implications to individuals with OA, who view it as a normal result of ageing. Thus rather than lives being 'biographically disrupted', the illnesses which are encountered may be 'biographically anticipated'.

A further issue related to the biographical disruption theory is the possibility that biographical disruption may be a cause of chronic illness, rather than chronic illness being the cause of the biographical disruption[161]. For example, G. Williams (1984) cited the case of a man suffering from RA who used his illness experience as a way of reinterpreting the work conditions that he believed contributed to his poor state of

health. For example, it was only after the man took on the 'extended responsibility' as a 'working gaffer' that things began to 'go wrong' (p.180[122]).

The concept of biographical disruption may be important for those individuals with OA and their experience of a TKR. Research has shown that although OA is universally considered to be a normal and integral process of ageing, it is also a source of biographical disruption[138]. The authors stated that despite the disruptive impact of OA symptoms on daily activities, the connotations of disability as being a normal part of old age meant that symptoms were 'played down', and many older people demonstrated a stoical attitude towards their arthritis. Furthermore, due to the societal and personal perception of degeneration on older age, individuals with OA were less inclined to ask for help, as the condition was not seen as legitimate or 'genuine'[138]. The experience of a TKR (major invasive surgery, the experience of being in hospital and the recovery process) may also represent a major disruptive event in an individual's life. However, no previous qualitative research has been conducted to explore this experience.

## Sociology of the body

Recent discussion and debate in the sociology of health and illness has focussed on the 'sociology of the body' or 'embodiment'. This has been associated with a critique of positivism and especially with a rejection of the legacy of R. Descartes (1596-1650). Cartesian dualism, as it is often called, proposes that the body and mind are separate, thus all mental, spiritual or emotional events were treated as separate from the body. In this perspective, the human (or self) owns the body, and that the body is separate from the self[165]. This view has had an important impact on the development of theories of knowledge, but in recent years, philosophers have rejected dualism, emphasizing instead the interaction of mental, physical and cultural phenomena. Based on the beliefs of a number of philosophers, human beings are said to be not made up of two separate components (mind and body), but are 'embodied': all parts of the body are integral to the human being and cannot be separated.

> *'The vision of soul and body is not an amalgamation between two mutually external terms, subject and object, brought about by arbitrary decree. It is enacted at every instant in the movement of existence' (Merleau-Ponty (1962) quoted on p. 57[166])*

The body becomes the subject matter of attention when a biologically disruptive event, such as chronic illness, occurs[125]. Thus, when 'resistances' or 'difficulties' are

encountered, the body becomes profoundly problematic and uncertain. Individuals may in these circumstances, 'disembody' themselves from their bodies. For example, when an individual has severe pain, feelings of 'bodily betrayal' or alienation may result, perpetuating the Cartesian dualism described above. As a result of pain and suffering, the self is shattered into a series of 'lived oppositions'[167]. Blaxter's (1983) study of women discussing the causes of disease found that in normal speech, a disease becomes separated from the body and the injured parts of the body can become an 'it' or 'an arthritis'[136]. However, Williams described that a loss of confidence in the body is quickly followed by a loss of confidence in the self[125].

As a consequence of the loss of self, individuals not only have to suffer the physical disabling effects of illness, but also the sense of loneliness, isolation, dependency and stigmatisation[157]. Chronically ill persons frequently experience a 'crumbling away of their former self images without simultaneous development of equally valued ones' (p.168[157]) in several ways. First, the chronically sick may lead restricted lives and may cease to exercise independence and autonomy in their daily lives. They are reminded of losses of their former selves by their inability to do what others take for granted. Second, many may experience social isolation. This may take the form of inability to participate in shared social activities and also be in the form of a breakdown of reciprocity – they are unable to return favours on which active friendships depend. Thirdly, individuals may feel they are a burden to others. Chronic illness may result in considerable dependence on others, which may in turn lead to feelings of uselessness. Finally, the loss of self through being publicly discredited makes the individual feel as though others treat them either as if they are not present or as if of diminished intellectual capacity. It is the positive valuation of independence and self-reliance by society that devalues the individual with dependency needs. Charmaz described how chronically ill people are involved in a constant struggle to lead valued lives and maintain definitions of self which are positive and worthwhile. This is difficult as cultural definitions of disability devalue the individual and interactions with others may constantly undermine individual's sense of self worth. Frank (1991) also commented on how society impedes or denies certain possibilities of living both in and with our bodies, and how individuals attempt to recover these very possibilities[168].

In a more recent study Charmaz stated that individuals with a chronic illness adapt to their condition, which means they alter their life and self to accommodate to bodily

losses and limits. Thus, the lost unity between body and self is resolved[169]. From 140 interviews about the experience of chronic illness and the body, she found that the process of adapting consisted of experiencing and defining impairment, making identity trade-offs and by surrendering to the sick self[169]. Thus, a person ceases to struggle against the illness and against a failing body, and therefore 'anchors bodily feelings in self' (p.672[169]). This differs from being overtaken by or giving up to the illness, as the surrendering is active and intentional. Thus, adaptation to the restraints of a chronic illness represents a more optimistic view of illness experience as a form of self-development and liberation.

Emotions may affect the way in which the body, illness and pain are experienced. For example, an emotion, such as grief is inseparable from its 'gut churning, nauseating experience', whilst physical pain is associated with displeasure, anxiety, sadness, and anger[167]. Lupton's qualitative study of 41 individuals views of emotions provided evidence to suggest that when 'people bottle up' emotions, this has a negative impact both physically and emotionally[170]. Pent-up emotions were also thought to be parasitic: turning the inside of the body 'bad' if emotions were not released. For example, one interviewee stated that 'emotions eat you up, I think that if you're continually not expressing them, they will eat you up inside. They could become ulcers, arthritis' (p.92[170]).

The process of narrative reconstruction, coping, strategies and styles of adjustment play a central role in the practical and symbolic realignment between body, self and society[125]. Research studies using embodied perspectives illustrate how people manage problems in illness; the notion of the 'mindful' body was introduced by Scheper-Hughes and Lock in 1987[171]. For example, in Price's phenomenological study of chronically ill people (asthma or multiple sclerosis (MS)), many patients had developed high levels of body awareness and skill in self-management. Price called this 'body listening'[172]. Other descriptions included "tuning into my body" or " reading the body". In describing the complexity of living with complex and ambiguous illness, such as arthritis, MS, diabetes and colitis, Strauss *et al* spoke of the necessity of paying attention to symptoms and "redesigning" one's life over the course of the illness in ways that will preserve function and preferred life style[149]. Positive practical and symbolic actions are taken by individuals with chronic illnesses in order to restore meaning and counter the effects of symptoms and treatment[124] (see Coping with chronic illness section below).

## Body Image

The ways in which individuals understand, experience and talk about emotions is highly related to the sense of body image[170]. The body is an important feature of all social interaction, because body image is regarded as an inevitable perspective of the presentation of the self. Grosz (1994) describes body image as:

> *'a map or representation of the degree of narcissistic investment of the subject in its own body and body parts. It is a differentiated, gridded, and ever changing registration of the degrees of intensity the subject experiences, measuring not only the physical but also the physiological changes the body undergoes in its day-to-day actions and performances' (p. 83[173])*

The idea that body image is socially mediated and impacts upon not only how individuals feel about themselves but also on the social relations was confirmed by Williams and Barlow's (1998) study of individuals with RA. They demonstrated that regardless of gender, age, type of arthritis and disease duration, arthritis can have a profound impact on perceptions of the body[155]. The individual's physical constraints made them feel uncomfortable in certain social settings, and they feared their altered bodies might undermine how significant others felt about them. The impact of RA led patients to believe that their body became the focus of attention in the social world, and hid the 'true' person inside. Feelings of self-consciousness, especially when in contact with strangers or partners provoked feelings of being different and highlighted fear of stigmatisation. Thus, a number of the informants made particular efforts to improve their appearance – to try and bring their perceived body image more in line with ideal images. For men, the main concern centred on loss of physical functioning and fitness together with a strong emphasis on body care and maintenance. Women, on the other hand, were more concerned about appearance-related issues, the visibility of arthritis, difficulties encountered with positive self-presentation involving cosmetics, jewellery and clothes. In the case of one woman, she would go on 'binge shopping' for clothes and make-up to present an 'image which looks good' (p. 136[155]).

Body image in individuals with OA may be important as visible signs such as walking sticks, limping or grimacing with pain, may affect the person's perception of their body image and their views on how others see them.

## The body in relation to technology

The development of modern medicine has provided the technology to replace bodily functions and organs, and to repair and upgrade the performance of the human body[174]. For example, with the advent of cosmetic surgery, bodies can be reshaped, restyled and rebuilt, and are becoming 'increasingly plastic'[175]. Titanium hips and knees, cardiac pacemakers and ear implants also create a body that is 'bionic' or a 'body-as-machine'[176], creating what post-modernists call a 'cyborg' (half human, half machine)[177]. 'The body is fitted into a new 'outer skin' of specially designed devices, machines and technological environments' (p.234[174]). Williams stated that the increase of new technologies designed to '(re)shape and control bodies have all meant that our sense of what the body is and what it might become is increasingly uncertain' (p.6[175]). For example, continual therapeutic procedures or prostheses can 'take over from' the incapacitated body[176]. Several questions may be raised about modern technology and how it affects people. For example, when something is attached or replaced in the body, such as a catheter or artificial replacement, what kind of impact does it have on the person as a whole? With embodied perspectives, it can no longer be assumed that people separate 'themselves' from a piece of technology or an appliance. Frank (1991) described how an appliance (such as a chemotherapy line) affixed to the body became a symbol of vulnerability:

> *'the line became part of my body, but the body was no longer entirely mine. The line was a symbol of cancer that I wore on my body, even when I felt pretty good, there it was, reminding me of all the aspects of cancer. I was vulnerable because it carried the risk of infection, and I was dependent on it during treatment' (p. 77[168])*

The loss of dignity that people may feel with technology may be due to the body becoming alienated from self[165]. When the body and the technology related to the body becomes an abstraction, a person can feel like the body is more like a broken down machine. Gadow said, 'the scientific body is the idea of the body... it is this construct, the body as scientific object—and not technology per se—that poses a violation of dignity and autonomy' (p.64[178]). Modern technologies in health care vary considerably. Any technology that is attached or inserted to a human being can take on a new dimension to their lives. No research has specifically examined the experience of total joint replacement and the effect it has on an individual's life.

## Managing medical regimens

Many chronic and disabling disorders, such as OA of the knee, have no cure. Thus, people with chronic disorders must learn to manage their symptoms and manifestations during everyday life. For example, people with RA learn how much activity is possible before pain rises to intolerable levels[130]. Daily life is then planned or 'paced' and organised in ways that allows the individual to accomplish a few valued activities before pain intercedes[120]. Controlling regimens can include diet, drugs, and alternative treatments[123]. Some treatments can be as bad as the disease, consuming time, energy and financial resources and requiring hard work[130]. There are a variety of different interventions available to reduce pain, improve function and limit the risk of disease progression for OA[82]. Much of the literature is centred on the issue of compliance and non-compliance of medication.

Research indicates that one third to one half of patients do not follow prescribed therapies[179-181]. Compliance (although a value-laden term[182]) has been defined as the extent to which a person's behaviour coincides with health-related advice. It includes whether patients attend clinic appointments as scheduled, take medication as prescribed, make recommended lifestyle changes, and complete recommended investigations. Non-compliant patients can include those who do not take any of their medication, those who sometimes take their medication, and patients who exceed what their physician prescribed[183]. Traditionally, studies of compliance have tended to be very doctor-centred, assuming that patients want to or ought to be expected to follow doctor's orders. Thus non-compliance is seen as 'deviant', a problem to be remedied, and suggests that it is the patient's fault (due to ignorance or forgetfulness)[184]. It also implies that doctors know what is best for their patients, that they communicate this information clearly, that they are rational when prescribing treatments, and that they are the main contributors to decisions about medications and treatment[185]. This concept of compliance reflects the paternalistic model of medical decision-making, where the doctors are in authority and patients are passive 'objects' in the therapeutic relationship ('sick role'[152]).

However, in recent years, there has been a change in the way compliance is perceived. Donovan's qualitative study of 54 patients with suspected RA, showed that patients do not view compliance as an issue, as they make their own reasoned decisions about treatments based on their own beliefs, personal circumstances, and information available

to them[185]. Thus, within this perspective, the patient has a much more active role. They are not passive 'blank sheets' when they arrive at the clinic or consultation[186]. Instead they carry out a cost-benefit analysis, weighing the advantages and disadvantages of adhering to the regimen according to their lay beliefs and available information[185].

Similarly, a study examining compliance with physiotherapy in patients with knee OA supported the view that patients are active participants in the decision-making process[187]. It was found that initial compliance to physiotherapy was high because of loyalty to the physiotherapist. However, only five of the 20 were consistently exercising eight months later. Reasoning influencing compliance involved a number of issues; a) the willingness to and ability to accommodate exercises within everyday life – those who ceased exercising often cited conflict with regular routines which affected exercise programme, b) the perceived severity of symptoms – those experiencing severe pain and/or loss of mobility were most likely to continue to exercise, c) attitudes towards arthritis and co morbidity – those who thought that arthritis was caused by factors such as age, obesity and 'wear and tear' tended to have a resigned attitude towards their OA, thus, they found it hard to believe that physiotherapy could be effective and thus were less likely to comply; d) the perceived effectiveness of the treatment – high levels of compliance were closely related to the perception that physiotherapy was effective. Those who noticed an improvement in their knee symptoms were much more likely to comply than those who did not[187].

Thus, treatment regimens are not just automatically accepted. They are judged on the basis of efficiency or legitimacy, or both. They are also judged on a social rather than a medical basis. Thus, those individuals with the chronic illness know best about the treatments they need.

## Information, awareness and sharing

Information is important for reducing uncertainty, as it may help the individual deal with their illness and may allow for the development of management strategies[123]. It also demonstrates that the patient is 'active' in their search to understand why they have the disease and what will happen to them in the future, rather than 'passively' accepting their condition. Information can range from just knowing the diagnosis and prognosis to understanding the biomedical intricacies of the disease. This knowledge can sometimes produce inaccurate biomedical accounts, but often reduces a sense of

dependence by providing the basis for action, and the feeling of control over their lives[130]. Before seeking medical help, it is usual for a person to discuss their complaint with family members or friends – the network of 'lay' consultants[139].

Many patients expect their doctors to provide information about their condition. However, many people with chronic diseases are often dissatisfied with the type and amount they receive[188]. As stated earlier, patients with chronic disabling disorders can be difficult for a medical practitioner to manage successfully[130]. This is partly due to the lack of interventions which make a real difference to the patient's condition, as well as the narrow 'medical gaze' which is concerned predominantly with disease and excludes the social and emotional consequences for patients and families[130]. One of the difficulties between the doctor and person with the chronic disease tends to be communication problems[160]. For example, cultural, social, ethnic and educational differences and the situational aspects of the encounter can impede communication: 'not only is the patient confronting a professional, but in so doing s/he may be lying down while the doctor stands' (p.130[160]). Anderson and Bury indicated the need for a reorientation of the focus of care from repairing damage caused by disease to education and understanding for living with chronic illness[189]. Therefore, information, advice and support are among the most important interventions a doctor has to offer.

Information is often acquired from informal sources as well as from professionals[160], and as a consequence, the patient can become an 'expert' in their illness. This may be problematic, as the patient may doubt the doctor's level of expertise and diagnosis[159]. Studies have shown that in conditions such MS, patients become knowledgeable about the symptom-reducing effects of steroids and other anti-inflammatory drugs and about differing opinions of their side effects[127]. This study suggested that 'pooling expertise' of patient and practitioner is a more useful way forward than the medical preoccupation with 'patient compliance'. Self-help groups are also used as a source of information by the chronically ill, where lay and professional perspectives on illness information can be discussed. Sharing experiences, realising that they are not the only one to have the disease, exchanging coping strategies are said to instil a sense of belonging[149]. However, while the numbers of self-help groups have expanded in the last two decades, they still only appeal to a very small segment of the chronically ill[123]. Narrative expression (stories, poems) of the chronic illness is also believed to result in a more optimistic view of illness experience[169,190]. As reality manifests itself as experience in individuals, stories

are fundamental to human understanding. In many therapeutic groups personal stories are told as a way of sharing experience in order to solve common problems[191].

## Family relations

Chronic illness is seldom a personal matter; the experience of illness 'falls as heavily on the family as on the patient, in terms of problems created for daily living and family life, and through the search by the family for adequate responses to these problems' (p.90[192]). Despite this major impact, relatively little sociological research has focused on the effect illness has on the family. Conrad stated that this may be due to both the medical view that the patient is a 'single insular individual' and also due to research which has predominantly focussed on the 'sufferer's world'[123]. The existing literature that has focussed on families highlights three prevailing concerns: the effect of illness on the family, the family as caregiver; and the sufferer's perception of the family.

The effect of illness on the family depends upon the type and severity of the illness, the level of patient's knowledge and awareness of the illness, the salience of those aspects of self that are lost on account of the partners lives (sexual intercourse, occupation, travelling), and how well the couple is able to come to terms with it[193]. Sociological research has identified several processes and changes that occur in families as a result of the discovery of an illness, the medical care and rehabilitation and the stresses in identity[194]. For example, the changing meaning of time in recovery, the influence of others on the identity of the disabled person and the 'clash of interests between hospital and home' have been explored[194].

The effect of illness on marital relationships has also been highlighted as important as the individual with the chronic illness can be restricted in their social activities[149]. Furthermore, although it is necessary for the patient to help control pain and fatigue, the healthy spouse can become frustrated because their social life is impacted too[160]. In addition, chores and responsibilities may need to be transferred to another family member. It has been found that spouses of individuals with chronic illness tended to report higher rates of depression, greater use of psychotropic drugs, poorer self-reported health, more relinquished social activities, and an increased number of new roles and responsibilities[195]. A recent cross-sectional survey of 79 persons with RA and their spouses found that certain passive coping styles were associated with lower marital satisfaction[196]. Linear regression analyses indicated that patients who reported lower

marital satisfaction had more education ($p< 0.01$), and more intense pain ($p< 0.10$), and used more escape into fantasy ($p< 0.01$) and less finding of blame ($p< 0.05$) in coping with arthritis, and were married to spouses who used more escape into fantasy in coping with the disease ($p< 0.001$). The spouses' marital satisfaction was not associated with the patients' use of these coping strategies. Those spouses who reported less marital satisfaction tended to be women ($p< 0.01$), and used more passive acceptance ($p< 0.05$) and less use of finding blame ($p< 0.05$) in coping with the arthritis.

Families can provide a great deal of the care-giving for the chronically ill. Strauss *et al* (1984) introduced the concept of 'kin work' to describe what kin do in relation to ill family members[149]. Different kinds of work were identified, such as comforting, clinical safety and empathy, which were shown to be essential when living with someone with a chronic illness[149]. The perception of the individual with the illness to their families also has its associated problems. For example, family help and support can create a stressful situation for both the person who must undertake more responsibility and the person who must admit to themselves that they have become more dependent[149]. Thus, even where families are able and willing to help, the person with a chronic disabling condition may feel that he or she is a burden and may refuse the assistance that is needed[130]. Research on families with OA experience has received little investigation.

## Coping with chronic illnesses

Of central importance to chronic illness is the individual's way of coping, and their ability to adapt to or control threatening aspects of the disease. Individuals who are chronically ill attempt to take positive actions in order to counter or minimise the effects of symptoms and treatment[125]. Attempts to realign the body, self and society can be made through their search for *meaning*. These meanings preserve a sense of self-identity and without such meanings, feelings of despair and isolation may develop. For example, as described above, William's (1984) study of RA showed how individuals undergo a process of 'narrative reconstruction'. The individual's biography is reorganised to account for the onset of their condition and their changing relationship to the world in which they live[122]. Drawing upon lay theories concerning the aetiology of illnesses is part of an ongoing process of coming to terms with chronic illness, and helps to re-establish a sense of meaning and order to the individual's world[197].

In addition to this search for meaning, more practical attempts are made to negotiate realignment between body, self and society. As such, a process of 're-embodiment'[125] occurs using various 'coping' mechanisms, 'strategies' and 'styles' of adjustment which individuals develop when confronted with chronic illness[124]. 'Coping' referred to the 'cognitive process whereby the individual learns *how* to tolerate or *put up* with the effects of chronic illness' (p.460[124]). Thus, feelings of personal worth and a 'sense of coherence' or 'potency' are given to the biographically disruptive experience of illness. For example, "normalisation", as a form of coping with diabetes, involves a process of keeping the pre-illness lifestyle and identity intact[198]. In addition, Scambler reported on a range of coping methods that people with epilepsy used to manage their condition. Building on Schneider and Conrad's[188] 'adjusted' and 'unadjusted' modes of adaptations, Scambler discussed the salience of having epilepsy and how this affected coping. When seizures were frequent the need to communicate and have the condition recognised within the family gave the condition particular salience. However, when seizures were infrequent or could be concealed, the condition played a far less important role in disrupting the person's identity. The status as 'epileptic' needed to be carefully and strategically managed. Thus, coping, involves 'maintaining a sense of value and meaning in life, in spite of symptoms and their effects' (p.461[124]).

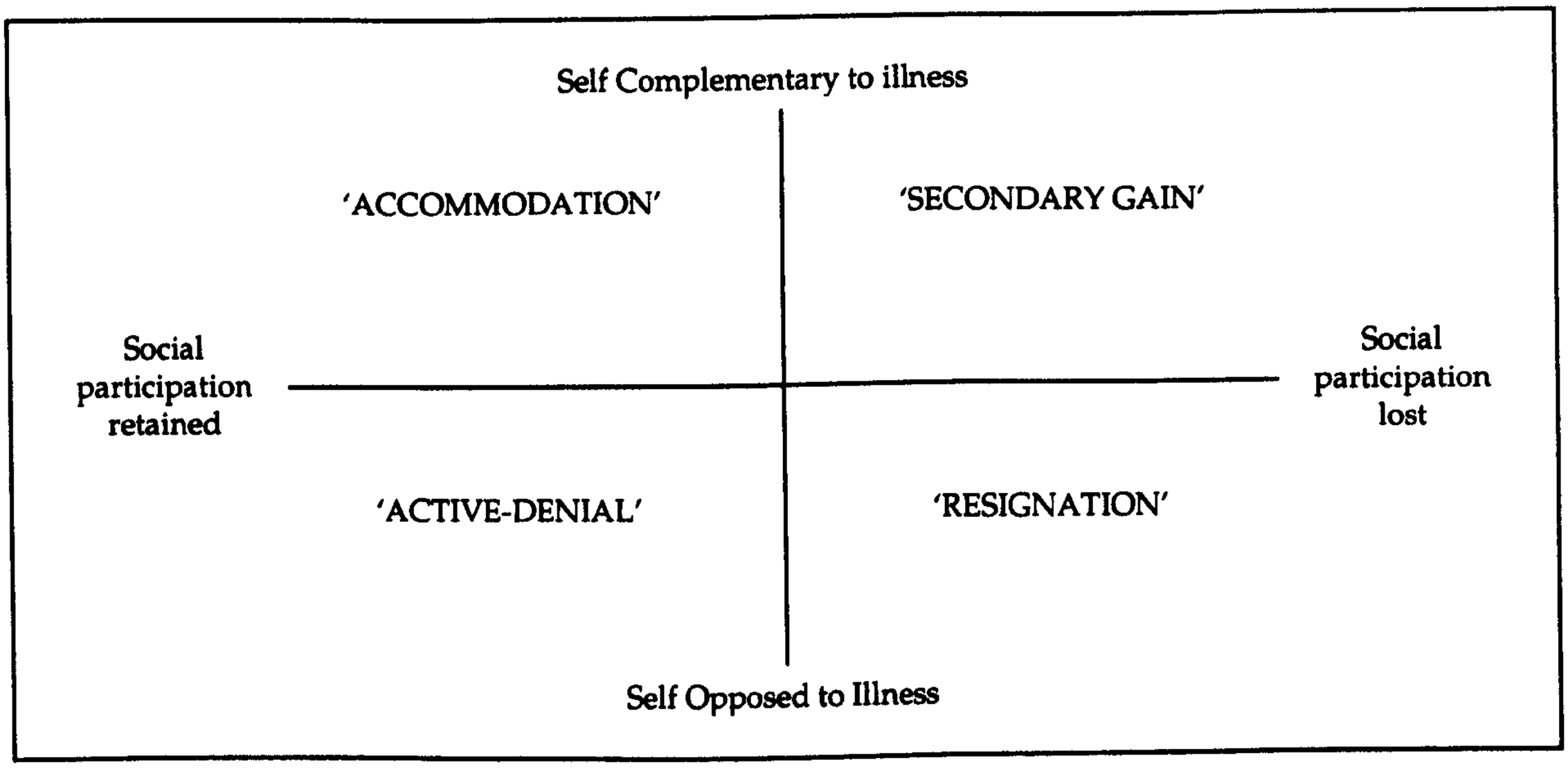
'Strategy', in contrast, captures the practical steps taken in order to 'mobilise resources' and minimise problems in everyday life, rather than the attitudes people develop. This helps to maximise favourable outcomes and maintain a sense of hope for the future. Studies such as Weiner's (1975), describe how individuals with RA are faced with contradictory strategies, namely the *inner physiological imperative* of pain and physical disability, and the *outer world of activity* involving the maintenance of what is perceived to be as near normal an existence as possible[120]. As a result, the individuals are left to 'juggle the hope of relief against the dread of progression' (p. 289[120]) and develop skilful management of symptoms of RA. For example, individuals both 'fight' the disorder and learn to live with the constraints, and use a variety of strategies such as 'covering up', 'keeping up', and 'pacing'. As Weiner suggested, this involves a process of 'spiral renormalisation' into lower and lower expectations and the development of new norms of action as the illness progresses. In addition, Shaul's qualitative study of 30 women with RA explored how they managed their chronic illness and the demands of their everyday life[199]. She illustrated the experience of living with RA as a transition process having three stages. The early phase of RA was described as "becoming aware," a time

when the early twinges were recognised and took on meaning. This was followed by a lengthy period of "learning to live with it," characterised by the use of trial-and-error strategies to cope with the illness and demands on daily life. A level of "mastery" of symptoms was achieved whereby the women managed everyday life in spite of RA. Shaul indicated that to achieve mastery, the individual must gain a sense of empowerment over the situation and develop a repertoire of strategies in order to cope with the changes in the illness process[199].

Finally, 'style', refers to differing symbolic ways in which individuals respond to, and present their illness, both to self and others. Personal resources, like 'modes of adjustment' (cognitive and behavioural efforts to cope with the stresses of chronic illness) are vital. Radley and Green (1987) distinguished four different 'modes of adjustment' in their study of chronic heart disease[200]. First, *'accommodation'*, which is the adjustment of one's life goals in response to illness, and the acceptance of such adjustments. Thus, an active and positive interest in outside activities is retained and the individual takes an active role in finding out about their illness. The next mode of adjustment is *'secondary gain'*, whereby the individual finds benefits and compensations from their illness. For example, enjoying advantages of privacy, social withdrawal, or dependency. Thirdly, *'active denial'* which is indicated by an attitude which minimises the condition, and which fights against the illness by attempting to continue a normal life. Finally, *'resignation'*, whereby feelings of passivity, hopelessness, and a view that illness has come to dominate life is evident.

These modes of adjustment are conceptualised in terms of their location on a cross cutting grid in which the self is either opposed or complementary to the illness and social participation is either lost or retained (see Figure 2.1). Thus, while the self may be complementary to the illness and social participation retained in 'accommodative' styles of adjustment, it remains opposed to illness in 'resignation' modes of adjustment and social participation is lost.

*Figure 2.1 Modes of adjustment to chronic illness*[200]




## Response shift

Another theoretical model which has received more attention in recent years, describes how patients confronted with a life-threatening or chronic disease accommodate to their illness[201] (similar to Radley and Green's "accommodation" mode of adjustment). This adaptation process is called "response shift" and involves the changing of internal standards (scale recalibration), values (the importance of component domains constituting the target construct) and the conceptualisation of quality of life (QOL) (redefinition of the target construct). These alterations may occur quickly, or they may evolve gradually over time (for example, acknowledging the decline of ageing)[202]. Furthermore, QOL can not only mean different things to different people but can also mean different things to the same person over a disease trajectory. The authors illustrated this process by telling the following story:

> *"A woman who, after hearing her diagnosis of osteosarcoma, told him (orthopaedic surgeon) that if her bone tumour prevented her from being able to walk, life would no longer be meaningful to her and she would prefer euthanasia. When the time came that this woman was confined to a wheelchair, she informed him that her life still held value for her but that if she were to become incontinent or bedridden, then life would loose its meaning and she would prefer euthanasia. However, when the time came that she was incontinent and bedridden, the woman stated vehemently that life still held meaning for her and that she was not ready for euthanasia" (p.1507-8*[201]*)*

This story illustrates that individuals' priorities change over a disease course resulting adaptation to the situation they find themselves in. There is also evidence in the literature to suggest that response shift plays an important (yet not explicitly measured) role in assimilating illness. It has been argued that patients' priorities change at the end of life, for example, existential, spiritual and social issues become more important[203]. Moreover, in a study using the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (a measure of individualised quality of life), patients with advanced incurable cancer almost universally rated concerns about their family as more important than health in determining quality of life. In addition, patients with a life-threatening disease or disability were found to report a stable QOL[204]. Response shift may also explain the reason why proxies tend to rate patients' quality of life as being worse than patients[205,206], and also the discrepancy between clinical measures of health and patients' own evaluations of their health[207]. Research suggests that that individuals lower their expectations and develop a new set of norms for action. For example, Reif (1973) stated that

> *'over the course of time, sick persons revise their expectations regarding what constitutes a normal or acceptable level of activity. That is, standards for performance are set in accordance with what is reasonable and possible, given limited capacity to cope with certain pursuits, at certain points in their illness. Bringing expectations into line with abilities is one strategy for coping with an otherwise untenable situation'*[208].

According to the 'response shift' model, changes may result from an interaction between: (1) a catalyst, such as a change in health status, (2) antecedents - stable characteristics or the individual's disposition, for example personality traits, (3) mechanisms - behavioural, cognitive and affective processes that accommodate changes in health status, for example comparing oneself to others[202], adjusting goals, adopting different routines, (4) response shift - "a change in the meaning of one's self-evaluation of QOL resulting from changes in internal standards, values or conceptualisations" (p. 1509, [201]), and (5) perceived QOL - the multidimensional construct incorporating physical, psychological and social functioning.

The concept of response shift has received little empirical attention. However, it may be important to consider in treatment evaluations, for example TKR, as it may serve to attenuate or to exaggerate estimates of treatment effects as patients adapt to the treatment or disease progression over time[209].

## Coping with osteoarthritis

Research suggests that people employ different coping mechanisms to deal with stressful incidents. These mechanisms may be cognitive (a way of thinking), or behavioural, in the form of a course of action[210]. In addition to the distinction between action and cognitive strategies, another main difference is between a preference for emotions-based coping or for problem-based coping[211]. Problem-based coping implies trying to do something about the difficulties, while emotion-based coping describes the attempts to minimise their emotional impact though adopting a particular attitude. The idea that some ways of coping are good and some are bad has been seen as being too simple[132]. In the case of problem-based or emotion-based coping, research has shown that in complex, stressful encounters people use a mixture of both[212]. In addition, there may be some occasions when a strategy might give positive results, and other occasions when it might be counterproductive. A review was undertaken of studies that examined the coping mechanisms of those individuals with OA. These studies are summarised in Table 2.1.

Studies that explore coping have predominantly used a number of questionnaires designed to measure these mechanisms. As can be seen from the Table 2.1, several structured scales for measuring coping and coping mechanisms have been developed: the 'Coping Strategy Questionnaire' (CSQ)[213], the 'Jalowiec Coping Scale' (JCS)[214], 'Ways of Coping Scale' (WOCS)[212], 'Coping Strategies Inventory' (CSI)[215], 'Pain Coping Inventory'(PCI)[216], the 'Summary of Arthritis Management Methods Questionnaire' (SAMM)[217], and the 'Vanderbilt Pain Management Inventory' (VPMI)[218]. The main aims of these scales are to assess the frequency and type of coping strategies used by those with chronic illnesses. The review raised several important themes related to coping with OA. It confirmed that individuals with OA used a variety of coping different strategies (both emotion-based and problem based) as a way of managing their pain and disability. In addition, certain coping strategies were found to affect psychological well-being of the individual, as well as the relationship between appraisal of OA symptoms and the choice of coping mechanisms.

A number of the studies indicated that some coping mechanisms were used more frequently than others, although the evidence for this was conflicting. For example, one qualitative study[219] found that the first and most frequently used coping strategy was 'palliative' coping which included strategies such as acceptance of the situation,

resignation, helplessness and avoidance. In contrast, other studies reported that the most utilised coping strategy was 'confrontive' coping and self-control (for example, "maintaining my pride and keep a stiff upper lip" and "I try to keep my feelings to myself") rather than 'palliative' coping, such as escape avoidance[220]. Use of 'confrontive' coping strategies were also confirmed by two other qualitative studies. One study of 20 interviews of individuals with OA demonstrated coping strategies such as 'refusing to give up', 'maintaining pragmatism' towards treatment options, and 'remaining in charge' were used to aid living with OA[135]. In addition, Tallon *et al*[221] presented data from a focus group which indicated that a stoical attitude was evident in patients with OA, including the attitude of 'carrying on regardless', taking medication as required, the use of aids to daily living, restricting movement, and resting. Remaining active as long as possible and exercises were also found to be good coping strategies. These findings indicated that patients prefer to actively manage their own condition, and illustrated the potential for educational and self-help interventions for knee OA[221].

The literature also demonstrated that certain coping mechanisms predicted psychological well-being, as well as observed pain and disability. For example, Blalock *et al* (1995) studied 10 different coping strategies in relation to psychological well-being among 300 community-residing OA patients. They found six coping mechanisms (problem solving, cognitive restructuring, problem avoidance, wishful thinking, turning to religion, and information seeking) were related to better psychological well being. In addition, they found that two of the coping strategies examined, self-criticism and social withdrawal, were used more frequently for social relationship problems. The authors stated that this finding was especially important given that higher levels of self-criticism and social withdrawal were predictive of greater psychological distress. They argued that problems in interpersonal relationships are more likely to elicit these maladaptive coping strategies and call for interventions to facilitate coping skills training specific to this area.

*Table 2.1 Studies examining the coping strategies of individuals with OA or hip/knee pain*

| Authors (year, country) | Study design | Sample | Outcome measures | Coping strategies |
|---|---|---|---|---|
| Keefe *et al* (1987, USA)[222] | Descriptive cross-sectional survey | 51 individuals with knee OA | Coping Strategies Questionnaire (CSQ), McGill Pain questionnaire, Arthritis Impact Measurement Scale (AIMS) | Arthritis patients who experience few catastrophising thoughts may be more able to recognise the value of their own efforts at coping with pain and may actually cope more effectively |
| Keefe *et al* (1987, USA)[223] | Descriptive cross-sectional survey | 87 patients with chronic knee pain | Coping Strategies Questionnaire (CSQ), Arthritis Impact Measurement Scale (AIMS) | Low levels of cognitive catastrophising were less functionally impaired, walked a 5 m course more rapidly and moved from a standing to a sitting position more quickly than patients who had high level of catastrophising |
| Downe-Wamboldt (1991, Canada)[219] | Descriptive cross-sectional survey | 90 women with OA | Arthritis Impact Measurement Scale (AIMS), Stress questionnaire, Jalowiec Coping Scale (JCS) | Coping strategies included palliative (resignation, acceptance), confrontive (active approach to OA) and emotive(worry, escapism)<br>Being aware of love and companionship of family and friends, the use of community services, an attitude of perseverance and maintaining a sense of humour also helped the individuals cope with their OA. |
| Burke and Flaherty, (1993, USA)[220] | Descriptive cross-sectional survey | Purposive sample of 130 elderly single women with OA | Ways of Coping Scale (WOCS), Arthritis Impact Measurement Scale (AIMS), Musculoskeletal Impairment Index | Most utilised coping strategy was self-controlling and the least was escape avoidance. |
| Blalock *et al* (1995, USA)[224] | Descriptive cross-sectional survey | 300 individuals with OA | Psychological well-being questionnaires, Arthritis Impact Measurement Scale (AIMS), Coping Strategies Inventory (CSI) | Problem solving, cognitive restructuring, problem avoidance, wishful thinking, turning to religion, and information-seeking were related to better psychological well-being. |
| Hampson *et al* (1996, UK)[225] | Descriptive cross-sectional survey | 82 individuals with OA | Personal Models of Arthritis Interview (PMAI), Summary of Arthritis Management Models Questionnaire (SAMM), Arthritis Impact Measurement Scale (AIMS), Vanderbilt Pain Management Inventory (VPMI), Profile of Mood States (POMS) | Appraisal of OA as more intense was related to use of more passive coping at 1 month and also related to more negative mood at 4 months.<br>Active coping was predictive of less depressed affective status. |

*Table 2.1 Studies examining the coping strategies of individuals with OA or hip/knee pain (cont'd)*

| Authors (year, country) | Study design | Sample | Outcome measures | Coping strategies |
|---|---|---|---|---|
| Kee (1998, USA) | Qualitative study | 20 individuals with OA (17 women, 3men) | Semi-structured interviews | Four themes identified for coping: "refusing to give up", "pragmatism towards treatment", "staying in charge", "tangible caring". |
| Hopman-Rock *et al* (1998, Netherlands)[226] | Descriptive cross-sectional survey | 157 individuals with hip or knee pain | Pain Coping Inventory, Sickness Impact Profile (SIP), household and sport activities with a validated interview method | People with chronic pain used relatively more "resting" and "reducing demands" as pain coping strategies. |
| Keysor *et al* (1998, USA)[227] | Qualitative study | 4 individuals with OA (aged between 25 and 45) | Semi-structured interviews | Behaviour change was difficult. However, once |
| Rapp *et al* (2000, USA)[228] | Descriptive cross-sectional survey | 394 older adults with knee pain | Knee Pain scale<br>Coping Strategies Questionnaire (CSQ) | Less catastrophic thinking and prayer, and stronger perceptions of pain control were associated with less disability and better physical function. |
| Baird (2000, USA)[229] | Qualitative study | 18 women with OA | Patient narratives | Strategies used to cope with 'living with hurting' and 'living with difficulty doing' included refusing to do activities, continuing to do activities, revising what one does, hunting for better ways, fixing what cannot be done, leaning on others and listening to others. |
| Tallon *et al* (2000, UK)[221] | Qualitative and questionnaire survey | 7 OA patients for the focus group.<br>112 people with knee OA | Focus group questions<br>Structured questionnaire | From the focus group, a variety of coping strategies were used including 'carrying on regardless', taking medication as required, the use of aids to daily living, restricting movement, and resting. Remaining active as long as possible and exercises were also good coping strategies.<br>From the questionnaire data, keeping active was perceived as the most helpful strategy. In addition, lifestyle adaptations, and maintaining a positive attitude. |

Another theme to emerge from the literature on coping with OA was the relationship between the way an individual appraised their OA symptoms and their choice of coping mechanisms. For example, 'catastrophising' behaviour, which is characterised by negative self-statements and overly negative thoughts and ideas about the future, has been shown to affect coping. Keefe *et al* in their study of 51 patients with OA reported that those patients who experience few catastrophising thoughts were be more able to recognise the value of their own efforts at coping with pain and therefore coped more effectively[222]. In a further study of 87 OA patients, they replicated these findings and found a similar association with physical ability. Those individuals who had low levels of cognitive catastrophising were less functionally impaired, could walk a 5 m course more rapidly, and could move from a standing to a sitting position more quickly than patients who had high levels of catastrophising[223]. Thus, they suggested that learned cognitive and behavioural coping skills may be useful for both managing pain and physical ability. This was also confirmed by Rapp *et al* (2000) who examined the role of pain coping skills in 394 older adults with knee pain and disability[228]. They demonstrated that less catastrophic thinking and prayer, greater ignoring and reinterpretation of pain sensations, and stronger perceptions of pain control were associated with less disability and better physical function.

The relationship between severity of OA and coping mechanisms has also been explored. Results from a prospective study of 157 community living older people with pain in the last month, reported that people with *chronic* pain used relatively more "resting" and "reducing demands" as pain coping strategies, than people with *mild* pain[226]. The authors concluded that the use of "resting" may be adequate to reduce pain severity in the short term, but in the long term this strategy may promote physical disability. Additionally, Hampson *et al* (1996) examined how the appraisal of OA symptoms determined the use of coping mechanisms[225]. In a prospective study of 82 older men and women with OA recruited from the community, assessments were made at baseline, one month, and four months. They found that appraisal of OA as more intense was related to the use of more passive coping (wishful thinking thoughts) at one month. Passive coping was, in turn, predictive of subsequent negative mood at four months. Intensity was also directly predictive of subsequent negative affective status. That is, participants who believed themselves to be sicker used more passive coping and were more depressed at follow-up. Active coping was not found to be determined by

primary appraisal. However, active coping was predictive of less depressed affective status. The authors concluded that the relationship between primary appraisals and subsequent passive coping and adverse affective impact had implications for interventions designed to enhance OA self-management and reduce OA impact.

The majority of the work related to coping with OA has concentrated on older people, mainly due to the fact that more older people experience OA. However, as stated in Chapter one, younger individuals, typically men with sports injury, also experience OA[44]. Only one study, using a qualitative methodology, explored the experience of living with OA as young and middle-aged adult[227]. Four informants between the ages of 25 and 45 years diagnosed with tibiofemoral OA were interviewed. They found that living with OA involved pain, fear, isolation, helplessness, and loss of function, identity and perceived control. The informants struggled with adapting to their pathology and behaviour change and activity modification were difficult. The authors felt that age may be an important aspect of helplessness as people who had difficulties performing their roles at earlier ages may experience helplessness more than older adults who attribute their pain and loss of function to general ageing process.

In summary, different types of coping mechanisms are used by individuals with OA, ranging from self-control and stoicism to resignation and avoidance. Although there was no consensus as to which coping strategy was considered the best, the review demonstrated that the most common type of coping tended to be 'confrontive' coping. Thus, the individuals with OA were more likely to use coping strategies that included stoicism, determination and self-control. One study indicated that particular coping strategies predicted better psychological well-being, although the evidence for this is limited. In addition, the review illustrated how behavioural traits such as 'catastrophising' can affect coping, as well as the perception of the severity of OA symptoms.

## Summary

The experience of OA has received relatively little sociological work, compared to other conditions, such as RA. Much of the work has concentrated on how individuals cope with OA. This may be because OA is often portrayed as an inevitable and 'normal' condition, and as a consequence, research has predominantly been focussed on how individuals cope and manage symptoms, rather than how they view their condition.

However, recent research (as discussed in this chapter) has shown that the experience of OA can be highly disruptive and the label of having a 'normal' condition can cause problems[138]. Thus, the chronic illness themes discussed above may have as much importance to OA as other chronic illnesses. Furthermore, the experience of undergoing a major operation such as TKR has not been explored. Due to the major impact OA and TKR has on society and the individual, it is important to understand the experience of this condition and procedure from the patient's point of view.

The focus of the next chapter is on the relationship between patient expectations and satisfaction. The common outcome measures used in assessing OA and TKR are also explored.

# CHAPTER 3: EXPECTATIONS AND OUTCOME

## Introduction

The first section of this chapter describes the literature on patient expectations and its relationship to an individual's satisfaction. This is followed by an examination of the outcomes and assessments of OA and TKR.

### Patients' views

Patients' views have received growing acknowledgement in the planning and delivery of health care[230], most notably since the publication of the government's White Paper, *Working for Patients* (1989) and the introduction of the Patient's Charter (1991). The majority of this work has focussed on the patient's satisfaction with medical care and towards patient expectations. Commentators suggest that there is a substantial link between satisfaction and the fulfilment of expectations[231-236]. However, this has not been explicitly defined in the literature and there is little theoretical or empirical support[237,238]. This section will describe the definitions and types of expectations that individuals can have, and the influences that may modify or develop them. The few existing conceptual models that have been developed for expectations will be discussed, along with the research exploring its relationship to patient satisfaction.

### Definition of expectations

The nature of expectations is complex. Stimson and Webb stated that:

> *'...expectation seems to be a concept which, like so many others used in describing social aspects of medicine (such as patient satisfaction), is extremely difficult to examine analytically' (p.27[239])*

Various types of expectations have been identified. For example, the 'ideal' expectation represents the individuals' aspirations, desires, wants or preferred outcome[237,240-243]. The 'predicted'[237] expectation, commonly described as the expected[240], practical[243] or probable[242] expectation, relates to what individuals actually believe will happen in a medical encounter. The 'normative'[237] or 'deserved'[240] expectation represents what the individual thinks should happen, related to a subjective evaluation of what is deserved in a situation. The 'unformed' expectation refers to the situation when the patient is unable or unwilling to articulate their expectations[237]. This may be because they do not have any, or they may find it difficult to express them or they may not want to express

their feelings, due to fear or anxiety. The unformed expectations may be just a temporary phenomenon prior to experience and may include the 'taken for granted' attributes of care. This is not an exhaustive list of the different types of expectations that have been used, but they generally illustrate a common theme: that patients have a concept of an ideal expectation but also a view about of the probability of achieving this. However, although these different types of expectations have been commonly used by studies, the boundaries remain blurred.

Despite the differing types of expectations, there is some consensus that expectations are a type of belief[237,244,236]. This allows expectations to be cognitive, influenced by information and individual experience, and capable of modification over time. Once established, beliefs manifested as expectations are thought to affect attitudes[245]. Thus, in the context of a medical setting, an expectation can be a belief about an object (needs, medical treatment, waiting time) and as an attribute of that object (urgent, curative, long)[244]. They can be formulated at the outset of a medical encounter on the basis of the information available at that time (from the surgeon, from experience of others, or prior personal experience) and can also be modified by experience (the patient's personal involvement with the medical care system)[246]. Market research has also stated that experience may actually be modified by expectations[244]. This process could be a contest between two psychological forces, one suggesting that patients should alter their perceptions of reality to conform with expectations and another suggesting that patients should alter their expectations to conform with reality.

## Expectations and satisfaction

Measuring and studying patient satisfaction, in particular with TKR, is important for a variety of reasons. Greater satisfaction seems to be associated with higher overall health status, and vice versa[247]. Patient satisfaction has also been shown to affect the compliance with, and acceptance of, treatment and outcome of care. Patients who are more satisfied with their experience of health care are more likely to follow the advice they receive, and adhere to medical regimens[248]. In addition, dissatisfied patients are more likely to fail to re-attend [249], to change their doctor or health plan[250] or to resort to unorthodox medicine[251].

Satisfaction with health care is said to be influenced by a number of factors. One of these is the degree to which the experience matches prior expectations[231,234-236]. For

example, Jackson *et al* (2001) assessed 500 adults (post-visit, two weeks and three month follow-up) presenting with a physical symptom at a general medicine walk-in clinic in USA[234]. They reported that at all time points, the presence of unmet expectations markedly decreased satisfaction: immediately post-visit (OR: 0.14, 95% CI: 0.07-0.30), two weeks (OR: 0.07, 95% CI: 0.04-0.13) and 3 months (OR 0.05, 95% CI: 0.03-0.09). Thus, they suggested that a lack of unmet expectations was a powerful predictor of satisfaction at all time-points. Calman (1984) defined quality of life in terms of 'the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experience' (p.124[232]). Where there is a wide discrepancy between expectation and reality, then quality of life is low. Calman's model emphasised that part of a doctor's role may be to help patients have more realistic expectations, particularly at the point where the focus of care is changing from curative to palliative. Larsen and Rootman (1976) also predicted that the closer the physician's role performance is to a patient's expectations, the more satisfied the patient will be with the physician's services[233].

However, research suggests that even if patients have specific expectations for the health care visit, physicians are frequently unaware of these desires and consequently fail to recognise or address them[252]. There is also some evidence that patients' expectations of treatment differ from those of health care professionals[253]. For example, anecdotal evidence suggests that a surgeon's priority when performing TKR is the relief of pain, whereas, patients tend to expect (and prefer) function improvement[254].

To fully understand the nature and causes of expectations and satisfaction, personal frameworks and social contexts need to be addressed. When eliciting patients' views and expectations, the assumption in most studies is that they are trustworthy indicators of their health or health care. This implies that patients' views are balanced and well informed and that they have access to all the information they require. This is not necessarily always the case with all patients. For example, personality characteristics may reflect expectations. Pessimistic or optimistic personalities may lead to negative or positive expectations. Research has found that patients with positive expectations tend to minimise or ignore unfavourable symptoms that would generally be perceived as a sign of worsening health[255]. In addition to helping patients ignore undesirable symptoms, positive expectations are said to focus the patient's attention on improvement in health. Thus, when health improves, no matter how minor, the change

is perceived as proof of significant progression[256]. On the contrary, depression, which often accompanies illness, including OA, may make patients less optimistic, and therefore hold more negative expectations about a treatment. If expectations modify perceptions of experience, these patients may not be satisfied even when circumstances dictate satisfaction[244]. In addition, emotions may be so intense that it may lead to difficulties in the patient describing their feelings and expectations, simply because they are so personal and abstract in nature.

Age and gender differences have also been found to affect expectations[257]. McGrory and Becker (1997) surveyed 266 patients undergoing THR or TKR about their concerns and expectations[258]. They found that older patients were less concerned about surgery than younger patients. In addition, women were more concerned in their ability to do postoperative therapy, walk with crutches, take care of themselves after surgery, arranging for help at home, and their ability to get in and out of the bath. Men were more concerned than women only in their ability to lift objects after surgery. They also found that patients who had reported a previous surgery were less concerned about surgeon age and not knowing what to expect. Furthermore, patients who had reported a previous complication were more concerned with the cleanliness of the hospital, nursing care and risk of getting an infection.

The context within which the expectation/satisfaction relationship is set is an important aspect. Knowing what to expect from medical treatment is sometimes difficult to predict[244,259]. In these ambiguous circumstances, because patients may not know what to expect, they may not know when to be satisfied or dissatisfied. In the absence of baseline expectations, patients may fall back on faith in the consultant or use the attitude of the consultant as the sole determinant of satisfaction[259]. It may be that patients begin with no expectations, or just a limited set, due to a lack of any comparable experience or knowledge[237]. In addition, many expectations are likely to be changed as experiences unfold[244].

The fact that many realities are unanticipated may mean that even where expectations are articulated there may be no relationship between them. Fitzpatrick and Hopkins examined the relationship between expectations and satisfaction with 95 patients waiting to be seen by a neurologist[260]. They interviewed patients on two occasions: at the clinic prior to their consultation and at the patient's home, approximately two weeks after the hospital consultation. They found that patients had difficulty in articulating

their expectations, prior to the consultation. They had their own ideas about the cause, and what examinations might be appropriate, but their expectations regarding outcome were limited. Even after encouragement to express explicit expectations, they tended to be in terms of 'possibilities', not definite expectations. Thus, the expectations were 'fluid' and 'emergent' and were modified in the light of experience. The authors concluded that expectations recorded before the consultations were so tentative in form that they were unlikely to be the basis of strong reactions afterwards. In addition, they found little relationship between expressed expectations and subsequent satisfaction. Patients mentioned expectations before the consultation which were not met in the consultation but did not become the focus of critical comments afterwards[260].

The fact that expectations vary according to knowledge and prior experience, also suggests that they are likely to change with accumulating experience[261]. Bond and Thomas (1992), noted that increasing quality of care raises expectations[262]. In this analysis, as a result of increasing expectations 'high' levels of quality of care *may* gradually become associated with 'lower' levels of satisfaction. If the models associating satisfaction with the fulfilment of positive expectations are valid, then the high levels of satisfaction which are constantly reported from health care suggest that the large majority of patients are either very happy with almost everything, or that patients' expectations are generally low. This may be a similar process to the 'response shift' model (see p.60) which describes a number of processes whereby individuals change and accommodate to their illness[201]. The authors concluded that in order to examine the lack of variability, it is necessary to examine detailed characteristics of patients as well as a number of sociological and psychological issues[262].

## Basic conceptual models

The relationship between expectations and satisfaction has its strongest theoretical basis in psychology. Ross *et al*[244] described five models conceptualising the interaction between expectations and experience:

1. *Assimilation theory* draws on Festinger's (1957) cognitive dissonance theory and suggests that unfulfilled expectations of a treatment will create psychological discomfort. As a result, individuals will attempt to reduce this discomfort by minimising the differences between their expectations and experiences. When

perceptions of performance differ only slightly from expectations, there is a tendency for individuals to displace their perceptions towards their expectations.

2. *Contrast theory* proposes the opposite effect to the assimilation theory. It predicts that when expectations are not matched by actual experience, the contrast between expectations and actuality will cause an individual to exaggerate or magnify the incongruity.

3. *Assimilation-contrast theory* combines the theories of assimilation and contrast in accounting for the effects of unfulfilled expectations. This interactive model predicts that individuals will assimilate the differences between expectations and experiences when disparity is low; the opposite will occur of the disparity is large. The theory is based on the assumption that individuals have gradients of acceptance and rejection. Thus, individuals with moderate positive expectations and poor experience may evaluate care positively and be satisfied. Conversely individuals with moderately negative expectations and good experience may be dissatisfied. Individuals with extreme positive expectations whose experience does not fulfil their expectations will tend to magnify the discrepancy, causing considerable dissatisfaction. La Tour and Peat introduced a new complexity to the model by stating that the ambiguity of the treatment being evaluated will determine how assimilation and contrast effects operate. Assimilation effects occur in reaction to ambiguous predictions of outcome, while contrast effects result from more certain predictions of outcome[259].

4. *Generalised negativity theory* posits that an individual whose expectations are unfulfilled will judge a treatment to be less pleasant than they would have done in the absence of previous expectations. This theory states that any unfulfilled expectations, even those that might be more positive than expected, will result in a negative assessment.

5. *Adaptation level theory* suggests that outcomes are perceived only in relation to a standard, or adaptation level. Once an adaptation level is created, subsequent evaluations – either positive or negative – will remain close to the original level. Only major influences on the adaptation level will change the final evaluation. Thus, the adaptation level is an anchor for evaluations. In the expectations-satisfaction link, expectations serve as the adaptation level and reference point for satisfaction.

In summary, there appears to be basic agreement among the theories that initial expectations interact with subsequent experience to result in satisfaction or dissatisfaction. However, these theories have only been tested in market research, and do not appear to have been the subject of empirical research in health care.

Few of the studies that have attempted to measure patient expectations in patient satisfaction have provided a theoretical perspective or model[238]. Of those that have, the most well known model was proposed by Linder-Pelz (1982) who tested the value-expectancy theory[236]. Patient satisfaction was defined as a positive attitude, which was related to what patients believed the care would provide, and their evaluations of their care attributes. Attributes were seen as distinct dimensions of health care (access, efficacy, cost, convenience). Expectations were defined as a subset of beliefs; representing the information an individual had about an object (the linking of an object to some attribute). Satisfaction was directly related to the sum of the products of beliefs (expectations) and valuations (values) scores regarding various aspects of care.

Three alternative theories to the value-expectancy models of satisfaction have been identified by Lawler (1971)[263]: the discrepancy theory, the fulfilment theory and the equity theory. Discrepancy theory describes satisfaction as being the perceived but not necessarily actual discrepancy between what an individual desires and what occurs (expectations in the context as desires). Thus, to receive less than one wants (desires, needs) results in a sense of deprivation, feelings of disappointment, and a sense of injustice. Fulfilment theory also defines satisfaction as the difference between rewards desired and rewards received. Satisfaction would vary positively with the extent to which perceived occurrence concurs with prior expectation. The final group of theories identified by Lawler are equity theories; these propose that satisfaction is the perceived equity, and is achieved through comparison with others. Swan (1985) stated that a patient's perception of hospital performance would influence the extent to which their overall expectations and perceptions of equity would be met[264]. The fulfilment of these expectations (equitable treatment) would affect overall satisfaction, which would predict patients' intention to revisit hospital.

Three of these theories: the value-expectancy theory, the discrepancy and the fulfilment theories, have been tested. Data, including patients' values and expectations, were collected from 125 first time patients at a primary care clinic[265]. This included patients' health care values, expectations, and sense of entitlement to care, which were collected

immediately prior to seeing a physician; the individual's post-visit satisfaction with different aspects of care was also collated. The overall conclusion was that very little satisfaction could be explained in terms of expectations and values despite there being some correlation. Furthermore, satisfaction was unrelated to fulfilment theory and inversely correlated with discrepancy[265].

A criticism of these models is that they have not been tested extensively. Although all three posit that satisfaction is the difference between what is desired and what actually happens, they do not clarify whether the desires are expectations, preferences or 'what should be'. Thus, while there is evidence to suggest that patient's expectations and values are involved in evaluations, they do not appear to be related simply.

## The relationship between expectations and satisfaction in surgical studies

The relationship between expectations and satisfaction has been examined in a number of settings: primary care[266,267,268,239,269], clinical consultations[270,271,272,273,274], and pain therapy[275,276]. For the purpose of this thesis, only those studies relating to surgical procedures were reviewed: a total of 22 articles (see Table 3.1). The studies reviewed reported on a number of surgical procedures: total hip replacement (4), oral surgery (3), surgery for lumbar spine stenosis (3), surgery for gynaecological cancer (2), hip fracture (2), knee surgery (1), cosmetic surgery (1), foot surgery (1), heart surgery (1) surgery for benign prostatic hyperplasia (BHP) (1), temporal lobe surgery (1). Two studies examined more than one surgical procedure: one study studied three elective procedures (hernia repair, cholecystectomy, parathyroidectomy), and another studied three surgical procedures (hernia repair, cyst removal, or haemorrhoidectomy). The majority of the studies relied on quantitative methods, with only five using qualitative techniques. Most of the studies measured expectations prospectively (16) while others relied either on retrospective measurement (2), case studies (2) or cross-sectional designs (2).

*Table 3.1 Studies examining the relationship between expectations and satisfaction of surgery*

| Authors (year, country) | Study design | Sample | Outcome measures | Main findings |
|---|---|---|---|---|
| Burton and Wright[277] (1980, UK) | Retrospective questionnaire survey. | 88 patients who had had THR. | Interviewer administered 5-point rating scale of 'remembered' expectations. | Fulfilled expectations led to a better quality of life and greater satisfaction and vice versa. |
| George *et al*[278] (1980, USA) | Prospective questionnaire survey. | 38 patients undergoing oral surgery. | Pre-operation (week pre surgery) 4 questions about expectations<br>Post-operation –Likert scale assessments. | Patients' expectations about post-operative suffering acted as a 'self-fulfilling prophecy'. Patients who expected greater amounts of pain reported higher levels of pain, more disability and had a slower recovery after oral surgery. |
| Olsen and Laskin[279] (1980, USA) | Prospective qualitative study. | 52 patients undergoing orthognathic surgery | Pre-operation (not stated) – semi-structured interview.<br>Post-operation (6 months) – semi-structured interview. | Patients with unexpected outcomes during surgical experience expressed dissatisfaction. |
| Haworth *et al*[280] (1981, UK) | Prospective questionnaires survey. | 145 (OA and RA) patients undergoing THR | Pre-operation (1 month) - Interviewer administered scales.<br>Post-operation (9 months) – Interviewer administered scales. | Most patients had realistic expectations of improvement following THR. Those with RA, who tended to have poorer initial and final function, were no less satisfied with the amount they improved despite their remaining limitations.<br>The outstanding results of THR mean that patient satisfaction is high even if expectations are not fully met. |
| Macgregor[281] (1981, USA) | Case study. | 3 cases of patients undergoing cosmetic surgery. | Not stated. | Unrealistic expectations, as well as failure to understand the patient's expectations and preference, led to patient dissatisfaction with the outcome. |
| Rogers *et al*[282] (1982, USA) | Case study. | 6 cases of patients who had had a THR. | Not stated. | Unrealistic expectations of surgery lead to disappointment. |
| Wallace[283] (1985, UK) | Prospective questionnaire survey. | 121 patients undergoing gynaecological surgery. | Pre-operation (6-8 weeks)– questionnaire to assess expectations.<br>Post-operation -(immediately after surgery) Questionnaire | Patients who expected to feel pain reported a higher intensity of pain and more post-operative fear immediately after surgery than patients who did not have such expectations. The greater the discrepancy between expected and actual pain, the greater was the experience of distress immediately after surgery. Patients who expected the pain to be more intense than it actually was reported the least distress immediately after surgery. |
| Furstenberg (1986, USA)[284] | Cross-sectional interview study. | 11 individuals with hip fracture | Detailed observation and unstructured interviews. | Expectations about outcome were uncertain, and more likely to be expressed as fears. |
| Borkan and Quirk[285] (1992, USA) | Prospective cohort study. | 80 patients undergoing surgery for hip fracture. | Pre-operation (1 week) – interview and questionnaire to assess expectations.<br>Post-operation (3 months) interview and questionnaires. | Patients who had positive expectations for recovery and those who had greater experience were likely to have less negative change in ambulation from pre-fracture to 3 months, and a better overall ambulation at 3 months. |

*Table 3.1 Studies examining the relationship between expectations and satisfaction of surgery (cont'd)*

| Authors (year, country) | Study design | Sample | Outcome measures | Main findings |
|---|---|---|---|---|
| Flood *et al*[286] (1993, USA) | Prospective survey. | 348 patients who had surgery for benign prostatic hyperplasia (BHP). | Pre-operation – question about expected symptom improvement.<br>Post-operatively (3, 6, and 12 months) - Patient report of outcome. | Patients with more positive expectations for improvement after surgery were associated with greater self-reported improvement in health status up to a year after surgery. |
| Bellacosa and Pollack[287] (1993, USA) | Prospective survey. | 73 patients undergoing elective foot surgery | Pre-operation – (prior to surgery) 4 open-ended question about expectations.<br>Post-operation – (returned to full activity) 4 open-ended questions. | Fulfilled expectations led to satisfaction with surgery. However, not all patients responded to the question and the responses that were obtained were not categorised |
| Leedham *et al*[288] (1995, USA) | Prospective questionnaire survey. | 31 patients undergoing heart transplantation. | Pre-operation – (10 days) Patient expectations subscale.<br>Post-operation (3and 6 month) satisfaction questionnaire | Patients' with positive expectations were associated with good mood, adjusted to their illness better, and had a better quality of life. High preoperative expectations predicted later adherence to a complex medical regime. |
| Finlay *et al*[289] (1995, UK) | Prospective questionnaire survey. | 61 patients undergoing orthognathic surgery | Pre-operation (I month) expectations questionnaire.<br>Post-operation (3, 6, 12 month) - satisfaction questionnaire | Patients who were dissatisfied tended to have unrealistic expectations of post-surgical pain, numbness and swelling |
| Baker and Lyne[290] (1996, UK) | Prospective qualitative study | 7 patients drawn from 3 surgical list (either hernia repair, cyst removal, or haemorrhoidectomy) | Semi-structured interviews (preadmission, admission, pre-procedure, procedure, post-procedure, discharge, post-discharge) | Respondents had 'normative', socially defined expectations such as: they expected information, communication, amenities, trust, dignity and respect.<br>Respondents experienced difficulty in articulating their expectations of surgery. Expectations were phrased in terms of what could happen, rather than in terms of what they should expect. |
| Mancuso *et al*[291] (1997, USA) | Retrospective interview study. | 180 patients who had THR | Telephone interviews - 2 open-ended questions about expectations. | Lower rates of satisfaction were found in patients with a better preoperative condition, in patients who expected improvement in nonessential activities, and in patients who reported worse postoperative condition. |
| Wilson *et al*[292] (1998, Australia) | Prospective qualitative study. | 60 patients undergoing temporal lobe surgery | Pre-operation (admission) – 4 questions about expectations.<br>Post-operation (6 months) – semi-structured interview. | Patients who perceived the operation as a success tended to endorse 'practical' expectations preoperatively, rather than expectations of a psychological or social nature. In contrast, a perceived lack of success was associated with greater emphasis on psychological expectations preoperatively. |

*Table 3.1 Studies examining the relationship between expectations and satisfaction of surgery (cont'd)*

| Authors (year, country) | Study design | Sample | Outcome measures | Main findings |
|---|---|---|---|---|
| Inversen *et al*[293] (1998, USA) | Prospective questionnaire survey. | 257 patients undergoing surgery for lumbar spinal stenosis (LSS) | Pre-operation – mailed 5 close-ended and 2 open-ended questions about expectations.<br>Post-operation – 4 questions about satisfaction. | Patients with many pre-operative expectations reported more improvement in post-operative function than patients with few expectations. More ambiguous expectations for physical function were also associated with improved function and satisfaction at 6 months. Conversely, having more numerous pain relief expectations was associated with more pain and less satisfaction with pain relief. |
| Lutz *et al*[294] (1999, USA) | Prospective questionnaire survey. | 273 patients who had diskectomy for sciatica. | Pre-operation – (before surgery) 3 questions about expectations.<br>Post-operation – (12 months) 2 questions about satisfaction. | Patients with favourable expectations about surgery had good outcomes than patients with unfavourable expectations. |
| Haas and Dip[245] (1999, Australia) | Prospective qualitative study | 19 patients undergoing surgery for gynaecological cancer | Semi-structured interviews one week before surgery and 6-8 weeks after surgery. | No clear relationship between expectations and satisfaction. Unfulfilled expectations did not lead to less satisfaction. The patients were able to express satisfaction either with the care overall or with specific aspects of care, as well as being able to distinguish aspects of care with which they were dissatisfied. |
| De Groot *et al*[295] (1999, Netherlands) | Prospective study | 120 patients undergoing lumbar surgery | Pre-operation –3 open-ended questions about expectations.<br>Post-operation – questionnaire to assess disappointment. | Patients who do not expect to experience any post-operative pain are less disappointed after surgery than patients who expect to be in pain. |
| Jones *et al*[296] (2000, USA) | Prospective questionnaire study. | 445 patients - 3 surgical procedures, hernia repair (177), cholecystectomy (122), parathyroidectomy (146). | Pre-operation (before surgery) - one expectations question.<br>Post-operation (2 and 6 months) - mailed survey. | Patients' initial expectations could be categorised as "cure" or "health" outcomes: having less pain, getting better. It was only after surgery that patients identified their undeclared "care" expectations – based on their latent or normative expectations that they would be well cared for, that the system would provide the necessary information, and that the process of care would meet certain standards. |
| Mancuso *et al*[297] (2001, USA) | Cross-sectional survey. | 377 patients undergoing knee surgery – for survey-developments phase.<br>163 patients – for survey testing phase. | Pre-operation – open-ended questions about expectations.<br>Qualitative categories formatted into draft survey. Tested for reliability and validity. | Patients have multiple expectations of knee surgery and that these expectations vary by diagnosis, patient characteristics, and functional status.<br>Two knee surgery expectation surveys were developed (one for TKR surgery and the other for other types of knee surgery). |

The studies that explored the relationship between expectations and satisfaction did not illustrate any consensus as to the nature of this relationship. Two of the studies (one using a retrospective methodology and the other a prospective methodology) suggested that *unfulfilled* expectations lead to *dissatisfaction*[277,287]. In contrast, another two (prospective) studies reported the opposite: satisfaction can still be high even if expectations are not fulfilled[245,280]. In addition, two further studies (one prospective and the other retrospective) suggested that experiencing *unexpected* outcomes can lead to dissatisfaction[279,291]. The two case studies[281,282] and a prospective study[289] found that having *unrealistic* expectations led to dissatisfaction. Other prospective studies[285,286,288,294] stated that having *positive* expectations for recovery led to greater self-reported improvement and satisfaction in health. Leedham *et al* also reported that high preoperative expectations predicted later adherence to a complex medical regime[288]. Inversen[293] stated that patients with *many* pre-operative expectations reported more improvement in post-operative function than patients with *few* expectations. Inversen also stated that more *ambiguous* expectations for physical function were also associated with improved function and satisfaction at six months. Wilson *et al*[292], in their study of surgery for epilepsy, highlighted the importance of expectations and beliefs in shaping an individual's perception of outcome. They found that patients who perceived the operation as a success tended to endorse 'practical' expectations (for example, driving, employment, activities) preoperatively, rather than expectations of a psychological or social nature (for example, self-change, relationships). These patients experienced fewer postoperative seizures and psychosocial difficulties. In contrast, a perceived lack of success was associated with greater emphasis on psychological expectations preoperatively. These patients experienced a greater number of perceived postoperative psychological difficulties and more postoperative seizures.

Other studies looked at the psychological effects of expectations. It has been suggested that if a patient is mentally prepared before surgery, this will diminish his/her postoperative anxiety and disappointment. However, George[278] (1980) and Wallace[283] (1985) found that patients who expected to feel pain (and therefore mentally prepared) reported a higher intensity of pain and more post-operative fear immediately after surgery than patients who did not have such expectations. Additionally, De Groot[295] (1999) found that patients who did not expect to experience any post-operative pain, (and therefore not mentally prepared), were less disappointed after surgery than

patients who expected to be in pain. Thus, there is confusion as to the effect expectations have on satisfaction and psychological well-being.

Two of the qualitative studies in this review found no clear relationship between expectations and satisfaction[245,290]. Both studies stated that respondents experienced difficulty in articulating their expectations of surgery, similar to Fitzpatrick and Hopkins' (1983) work described above[260]. Expectations were expressed in a tentative way, more as hopes than as definite expectations: in terms of what could happen, rather in terms of what they should expect. This may be because they did not want to be disappointed after previously expressing high expectations, or they may have felt that their limited experience with knowledge about hospitals rendered them less than competent to form expectations about such factors. Furthermore, Furstenberg (1986) stated that hip fracture patients were uncertain about the outcome of their surgery, and were more likely to express their views as fears[284].

## Summary

Expectations are generally believed to play a central and dominant role in influencing satisfaction[241]. While this contention may be true, there appears to be much confusion and differential usage of the term, with a variety of definitions and concepts being adopted. In addition, it is clear from the above that there is a lack of common consensus on the relationship between expectations and satisfaction. This is likely to be, at least in part, due to the different methodologies used to assess expectations and satisfaction. As can be seen from Table 2.2, numerous different instruments for assessing expectations were used, indicating that there is no standardised method of measuring expectations[241,242]. However, it was apparent that while most of the quantitative studies illustrated some sort of relationship between expectations and satisfaction, the qualitative research provided evidence that there was no clear relationship. In fact, they indicated that individuals had a lot of difficulty identifying their pre-operation expectations. Furthermore, some commentators suggest that expectations cannot be properly formed until after the experience[298,239,296].

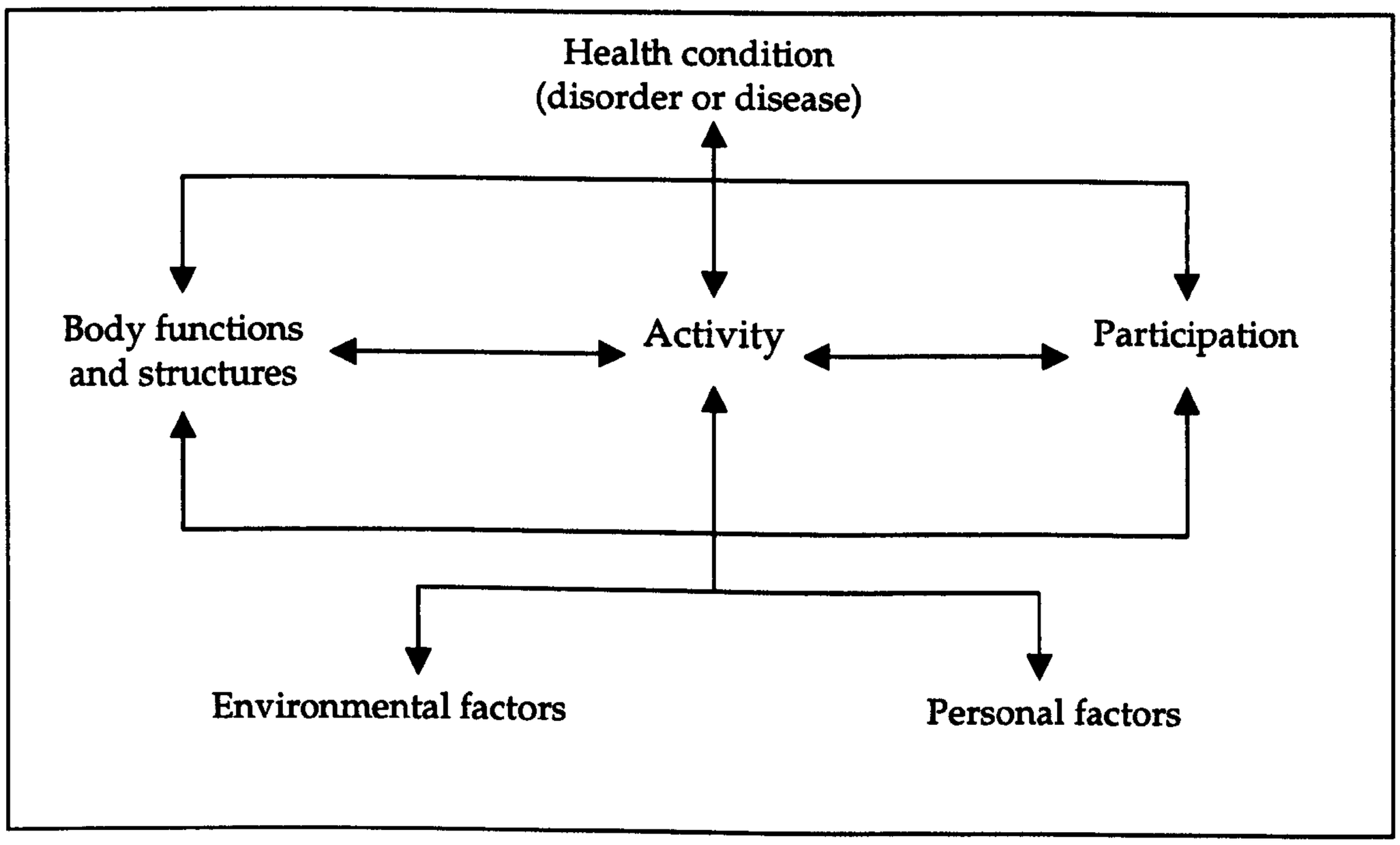
## Outcome measurement

Outcome measures examine the clinical consequences of a disease[299] and can be classified into different domains. Building on earlier work, outcomes have been classified using six D's: death, disease, disability, discomfort, dissatisfaction, and dollars[300,301]. This simple mnemonic characterises four distinct perspectives for studying outcomes: the traditional epidemiological paradigm (death and disease); the social psychological paradigm, emphasizing health-related quality of life (HRQOL) and functional status assessment (disability and discomfort); the consumer perspective (dissatisfaction); and the economic viewpoint (dollars). While the six D's concept is simplistic, it captures the range of attributes needed to assess outcomes. However, one of the most common and widely accepted methods of assessing outcomes in rheumatology is the International Classification of Impairment, Disabilities and Handicaps (ICIDH), which categorises health and health-related states into 'impairment', 'disabilities' and 'handicaps'[302]. This classification has recently been revised resulting in the International Classification of Functioning, Disability and Health (ICIDH-2). The terms 'impairment', 'disabilities' and 'handicap' have been replaced by 'body functions/structures', 'activities', and 'participation', in an attempt to extend their meanings to include positive experiences. The ICIDH-2 also lists contextual factors (environmental and personal) that interact with all these structures (see Figure 3.1) and provides a view of the different dimensions of health at both a biological and social level.

Body functions/structures (impairment) are defined as any loss or abnormality of psychological, physiological or anatomical structure or function (for example, pain, weakness and stiffness and estimates of subjective well-being). Activities (disabilities) include any restriction or the lack of ability to perform an activity in the manner considered normal (such as dressing, walking or preparing food). Participation (handicap) refers to the disadvantages suffered because of ill health (for example, social isolation and reduced income), and takes into account the availability of help and resources, and the importance accorded by each individual to these different activities. The 'environmental' factors make up the physical, social and attitudinal environments in which people live and conduct their lives. The factors are external and can have a positive or negative influence on the individual's performance as a member of society,

on their capacity to perform tasks or on body function or structure. 'Personal' factors are the particular background of an individual's life and living, and are composed of features that are not part of a health condition or health state. Factors may include gender, race, age, other health conditions, upbringing, fitness, habits religion or education. Personal factors are not classified in the ICIDH-2 because of the large social and cultural variance associated with them. However, they are shown in Figure 3.1 to show their contribution.

*Figure 3.1 Current understanding of interactions between the components of ICIDH-2*[302]




## Measurement of osteoarthritis

The measurement of OA can be categorised according to the WHO ICIDH-2 classification described above:

### Body functions/structures

This is synonymous with the assessment of abnormalities in structure and are measured either by clinical examinations or imaging procedures which are dependent on the judgement of the surgeon[303]. Thus, examination-based measures, such as stability, joint alignment and range of motion are commonly used, as well as radiographic imaging, MRI and scintigraphy.

## Activity

Activity measures tend to be subdivided into those based on observed tests of performance and questionnaires that assess functional capacity. Performance based measures, such as walk time[304], the stair test, and 'get-up and go test'[305-307] are seen to be the most direct way to assess the patient's function. However, such methods often involve the interaction between assessor and subject which may enhance or diminish the true performance. For example, simple encouragement from the observer has been shown to improve performance ($p < 0.02$ for the six minute walk)[308]. In addition, performance scores have also been shown to be dependent on a variety of factors including age, task repetition, warming-up, time of day tested, motivation and location[304,309].

During the last decade there has been considerable interest in capturing subjective views of health status and health related quality of life, from the patients point of view. Research in many areas of medicine and surgery have shown that the patient can provide reliable and valid judgements of health status and of the benefits of treatment[310]. This has stimulated researchers to expand the methods and metrics used to evaluate the effects of health services. As a consequence, standardised health status questionnaires are the method of choice for much of this research, and the use of both generic and disease-specific patient-centred measures are recommended in clinical trials of OA[311-313]. Disease specific questionnaires are designed to focus on the disorder under consideration and the patients' problems related to it. They include the Western Ontario and MacMaster Universities Osteoarthritis Index (WOMAC)[314], the Lequesne Index of Severity (ISK)[315], the Arthritis Impact Measurement Scale (AIMS)[316], and the Stanford Arthritis Centre Health Assessment Questionnaire (HAQ)[317]. In contrast, generic questionnaires have the potential advantage of being more able to measure side-effects or complications of the treatment, which may be unrelated to the condition itself[318]. For example, many people with OA will also have co-morbidities, and generic questionnaires are thought to obtain a more holistic view of health related quality of life. Generic measures include the Short-form 36-item (SF-36)[319], the Sickness Impact Profile (SIP)[320], and the Nottingham Health Profile (NHP)[321].

Thus, in the field of rheumatology, clinicians and researchers are faced with a choice of measures[318]. Although different in style, content and general approach to measuring patients' problems, they generally tend to focus on those aspects of patients' daily lives

that are most affected by ill health[310]. A number of issues must be taken into account when designing a questionnaire, such as reliability, validity and sensitivity to change. Considerable efforts have been directed towards evaluating and refining questionnaires in various settings.

Some observers argue that questionnaires are still limited because they ask a standard set of fixed questions of everyone and do not leave much room for individuals' personal concerns or problems to be expressed if they happen not to be included as a questionnaire item[322]. Donovan *et al* reported that people answering the NHP often misunderstood the NHP's questions and had problems with simple yes/no response options and this undermined the validity of the data[323]. Mallinson also found that people self-completing the SF-36 wrote comments on their questionnaires which suggested their interpretation of some items differed from the surveyor's intended meanings. They also had difficulty understanding the wording of the items and found some response options inadequate to describe their views[324,325]. 'The effect of unexpected variations or of flawed design is to create uncertain data whose validity is questionable' (p.11[325]).

Several instruments have been developed which are considered to have more meaning and relevance to individuals. The Patient Generated Index (PGI)[326], the Schedule for the Evaluation of Individual Quality of Life (SEIQoL)[322] and Measure Yourself Medical Outcome Profile (MYMOP)[327] have been developed and allow the patient to nominate those aspects of life which they feel are most important, to rate how badly affected they are in each of these areas, and to value improvements in each area. Only the SEIQoL has been used to assess OA and individual quality of life in patients undergoing hip replacement[322]. They showed that SEIQoL can be used to quantify the impact of disease and treatment on aspects of life that are important to individual patients[322]. Overall, patient generated approaches to outcome measurement has at least three important advantages over more conventional approaches: they have greater content validity; in certain clinical situations they are more responsive to change; and they are better able to incorporate the patient's own valuation of their quality of life. They also assess the extent to which reality departs from their own expectations, and value the relative importance of improvement in their chosen areas of life. However, these measures are not commonly used and a disadvantage is that data cannot be grouped. Nevertheless,

they represent advances in developing more patient orientated approaches to the measurement of health.

A major criticism of the ICIDH-2 is the absence of clear indications for the measurement of pain and mood. In the assessment of OA, pain is a primary symptom and psychological morbidity has been noted in patients with musculoskeletal disorders[299]. As stated in Chapter one, pain is an entirely subjective phenomenon, the perception of which is modulated by a variety of influences, and results in pain behaviours that may be observed[309]. The severity of perceived pain can only be rated by the sufferer. In contrast, pain behaviour can be rated by a trained assessor. It is thought that individuals who deliberately either augment or minimise their reported pain are probably in the minority. Pain can be assessed using a variety of techniques, including the Likert scale, visual analogue scale, ladder scale, pain questions, numerical rating scale, pain faces scale, McGill Pain questionnaire[328]. Several segregated multidimensional health status instruments, including the HAQ, AIMS and AIMS2 and the WOMAC contain distinct pain subscales.

A particularly important dimension is psychological well-being. There are numerous scales of psychological well-being, in particular those which are aimed specifically at detecting common psychiatric disorders such as anxiety and depression. Furthermore, factors such as self-esteem, locus of control and coping skills have been shown to influence quality of life and outcome[329,330].

**Participation**

Measures of participation for those with OA have attracted relatively little attention. The publication of the Disease Repercussion Profile (DRP), a valid and reliable measure of patient-perceived handicap, represents a significant advance on this previously underdeveloped area of musculoskeletal clinical measurement[331]. It assesses the impact of disease, the personal consequences of that impact, and the importance of these consequences in each of six areas of life: functional activities, social activities and interactions, relationships, finance or work, emotional well-being, and body image and self esteem. It produces a profile of the impact of the disease on quality of life. The assessment of patient-perceived handicap is considered essential to the clinical management of chronic disease because it provides the physician with clinically relevant

information about the meaning of disease for each patient, enabling treatment and intervention to be tailored to meet individuals' needs[332].

## Outcomes of total knee replacement

TKR has an established place in the treatment of knee OA[80]. As stated in Chapter one, TKR surgery is considered to be a safe and effective intervention which reduces knee pain and improves function[7,88-94]. However, systematic reviews of the studies examining the effectiveness of TKR reported that most studies were observational, and stated that the time to prosthesis failure or revision surgery were the main or only outcome measures, rather than patient-centred outcomes[80,333,334]. Williams *et al* in their 1992 review of TKR also stated that improvements in quality of life and patient satisfaction were often rarely considered and there was often an over-emphasis on physician-defined pain relief and measures of technical success[81].

Traditional methods for the evaluation of the results of a TKR tend to be based on the physician's assessment of pain and functional ability of the patient. The patient's assessment of the results has not been a part of this evaluation. The most widely used scoring system for TKR is the one advocated by the Hospital for Special Surgery (HSS)[115], which evaluates specific surgeon-determinants of knee function or patient characteristics. The HSS scale scores pain, function, range of movement, muscle strength, stability, and absence of fixed flexion to give a total of 100 points for a normal person. The result is classed as excellent with a score of 85, good from 71-84, fair from 61-70, and a failure below 60. The total condylar prosthesis has been shown to give 88% good or excellent results at 10-12 years[335,336], using this knee scoring scale. Furthermore, as stated in Chapter 1, a meta-analysis of studies of patient outcomes following TKR, stated that approximately 90% of patients reported to have a 'good' or 'excellent' outcome, using global rating scale scores[90].

Several difficulties are associated with this type of knee scoring measure which has important implications for studies examining the effectiveness of TKR. For example, these scoring scales were developed by orthopaedic surgeons and reflect the operating surgeons' perspectives[337]. In addition, the clinical examination, symptoms and functional limitations are summarised into one score using the knee scoring system. The use of summary scores does not make it easy to detect contrary trends between dimensions (for example, a patient may still experience pain, but have improved

function, range of movement, muscle strength and stability). Thus, data gained by summary or global ratings of outcome may miss important aspects of patients' views or fail to capture individual meanings or reasons.

The use of these physician based rating scales assumes that physicians and patients concur with regard to the degree of success of TKR. However, it has been shown that there is a marked disparity between the patient's and the physician's evaluation of outcome[338,339], especially when the patient is not completely satisfied with the result. A review of the literature suggested that it may be difficult for the treating physician to analyse the outcome of a particular therapeutic intervention objectively. Haworth *et al* compared the evaluations of pain, walking, and function by research occupational therapists with those by physicians after 71 THRs. When there was a major disagreement in the ratings between physicians and occupational therapists, physicians assigned better ratings to all three parameters[280]. Similarly, Lieberman *et al* demonstrated that the physicians' ratings of general health, walking ability, pain, and improvement in the quality of life tended to be better than those of the patients themselves[338].

There are several explanations for the differences between patients' and physicians' evaluations. For example, they may have different expectations with regard to the results of the procedure, or a different definition of what constitutes an excellent outcome. In addition, patients may not state their problems clearly for fear of disappointing the physician, and even if they state their problems clearly, the physician still may not comprehend the true nature of the pain and the patient's level of dissatisfaction[338]. Thus, the evidence which reports TKR to result in good or excellent outcomes on the basis of these knee scoring measures may be flawed and some commentators have stated that routine practice may not reflect the favourable published results[81]. The argument that has been persuasively made is that the success of treatment should be judged by direct reports of patients[340].

A number of health questionnaires (stated above) have been developed to be completed by patients for general use and have proved valuable when applied to patients undergoing TKR[91,340-342]. For example, studies have reported that the WOMAC and the SF-36 are the instruments of choice for evaluating the outcome of knee replacement surgery in OA[318,343]. The WOMAC is a 24-item self-administered questionnaire, which separately probes the three dimensions of pain, stiffness and physical function, whereas

the SF-36 generates a profile of eight dimensions for general health status. In the domains of function and pain, studies have shown that patients consistently showed significant benefit after knee replacement surgery[340,341,344]. A recent study reported that WOMAC measures improved significantly after one year for OA knee: there was a reduction of pain of 53%, reduction of stiffness of 43% and improvement in physical function of 43%. The SF-36 measures also showed significant improvement for pain (175%), physical function (197%), physical role functioning (275%), vitality (125%) and social functioning (119%)[345].

However, Dieppe *et al* reported that the wide variations in the outcome measures used made it difficult to come to a clear conclusion about the effectiveness of TKR. Furthermore, other factors, principally relating to study design and methodology have been shown to make interpretation of the studies of the effectiveness of TKR difficult[80,81]. For example, outcome assessment for TKR has been hampered by a lack of standardised terminology, missing or non-quantifiable clinical information, small samples, short periods of follow-up[81]. Many of the earlier studies of TKR have been shown to lack unbiased and systematic reporting of results[334], and were largely retrospective in design, with incomplete follow-up of subjects and often no consideration of the pre-operative status[81]. In addition, follow-up periods were variable and sometimes short and suggest that several prosthetic designs were used in the same series[80]. Other pitfalls have been reported, such as the lack of specification of case-mix, rehabilitation practices and surgical techniques[81]. Losses of cases to follow-up are common, and there was the problem that predictions of the expected failure rate often exceeded the period actually studied[81].

Thus, there appears to be a need for better quantitative studies, using patient based measures. However, even these measures may not explain the perception of outcome because the context and the experience of the intervention are not assessed. Rather than attempt to quantify a surgical result, a better methodology to use would be to ask the patient to express their views in their own terms. For this reason, a qualitative methodology was utilised in this study to explore the experience of a TKR from the patient's point of view. Such a qualitative study may also help to identify issues to be measured quantitatively.

## Summary

The primary aim of medical care is to improve or maintain the overall functional capacity and general health of patients[346]. Traditionally evaluation of medical treatment has relied upon measures of morbidity and mortality, and physician-based assessments. However, the recognition of the patient's point of view as central to the monitoring and evaluation of medical care has brought with it numerous approaches to the measurement of subjective well-being: including the exploration of patients' expectations and perceptions of outcome. Although TKR is considered an effective intervention, problems are apparent in the existing literature. For example, the reliance on physician-defined pain relief and function, an over-emphasis on observational studies rather than randomised controlled trials (RCTs), and the wide variations in the types of prosthesis and outcome measurement which make it difficult to come to any clear conclusions as to which patients do well and which do not[80]. The overall conclusion of this mainly quantitative research is that TKR is an effective treatment for knee OA with extremely high levels of success. However, some research suggests that these assessments may be over-optimistic and there is a need for further research, particularly that exploring patients' perceptions. This was the aim of this study and the next chapter describes the design of this research and the methods used.

# CHAPTER 4: METHODOLOGY, DESIGN AND IMPLEMENTATION

## Introduction

The intention of this chapter is to outline the rationale for using a qualitative methodology for this study. The philosophical background to qualitative research methods will be discussed, followed by a detailed account of the study's research design, data collection and analytical methods.

## Qualitative research

Qualitative research methods were developed in disciplines such as anthropology, sociology and cultural studies, in an attempt to explore and understand the social world[347]. The dominant feature of contemporary qualitative research is its diversity. It is a complex, changing and contested field – a site of multiple methodologies and research practices[348]. 'Qualitative research' therefore is not a single entity, but an umbrella term which encompasses enormous variety[347].

All of the qualitative research methods have a common basis: a reliance on the written/spoken word or the observable behaviour of the person being studied, as the principal source of data for analysis. The basic aim of qualitative research is to try to 'grasp phenomena in some holistic way or to understand a phenomenon within its own context or to emphasise the immersion in and comprehension of human meaning ascribed to some set of circumstances or phenomena' (p.376[349]).

### Interpretivist perspective

The interpretivist perspective to qualitative research is fundamentally concerned with meaning, and seeks to develop a way of understanding the 'complex world of lived experience from the point of view of those who live in it' (p.118[350]). This approach, first introduced by Husserl (1859-1938), developed from concerns about the limitations of quantitative data and methods. Positivism assumes an objective world which can be represented and measured by scientific methods[351]. Critics argue that in the process of developing quantified measures of phenomena, the context is stripped from their meanings[352]. In contrast, the interpretivists look at the extent to which the research adopts a *verstehen* (understanding) approach to knowledge: the ability to empathise with

the individual, to identify with him/her, and to illuminate the meanings which individuals attach to their behaviours and experiences[353]. Thus, to understand specific behaviours, such as an individual's response to illness, interpretivists claim that context is very important. The meanings people attach to their actions, and the ways in which people act out their everyday lives must be investigated. This perspective states that individuals interpret stimuli in ways which are continually revised as new experiences are encountered, which shapes their actions. Thus, the same stimuli can mean different things to different individuals and also to the same individual at different points in time[351]. There are several schools of thought within the interpretivist approach. Two of the sub-schools that relate most closely to this research, phenomenology and symbolic interactionism, will be discussed below.

***Phenomenology***

Phenomenology is a movement in philosophy to promote an understanding of the relationship between states of individual consciousness and social life[354]. Weber (1864-1920) stated that to understand particular social phenomena, the aim is to penetrate the subjective understanding of the individual[354]. To attain this aim, Weber introduced the method of 'ideal types', to be drawn by the researcher as a method of accessing subjective meaning. These 'ideal types' permit comparison of various aspects of social action in different societies and over time. By constructing and verifying the 'ideal types', the 'meaning of social phenomena can be interpreted layer by layer as the subjectively intended meaning of human acts' (p.7[298]).

The concept of 'ideal types' has been developed by other phenomenologists, such as Schutz (1899-1959), who argued that Weber failed to recognise the complexities of social life, and did not distinguish between the ways in which an interpreter modifies meaning[298]. Schutz acknowledged that the social world was not homogenous and stated that there was a 'fundamental difference between my interpretation of my own subjective experiences (self interpretation) and my interpretation of the subjective experience of someone else' (p.8[298]). Perceptions of the social world are complex, in that some are shared, and some unique to individuals[298]. To understand the social world, researchers have to examine the formation and structure of the life experiences that give meaning to actions. As Schutz said, 'meaning is a certain way of directing one's gaze at an item of one's own experience' (p.42[298]).

Schutz stated that the meanings that people hold in common are taken to be typifications or ideal types of the phenomena. At each moment in life, stocks of knowledge are available from past experiences, which are made up of typifications of the common-sense world. The individual anticipates and acts in terms of these generalised typical expectations, until something new is discovered that contradicts these expectations. These stocks of knowledge are the means available for action and they are constantly being re-confirmed or modified, as participation in life continues. Thus, knowledge, as a set of typifications, is a historically and socially derived cultural phenomenon.

Of particular importance to this study is Schutz's interpretation of meaningful experience. Schutz stated that experience of our actions can only be accessed reflectively, not at the moment it occurs. Schutz distinguished between two experiences:

1) indifferential on-going experience – the flux of experiencing from one 'now' phase to the next

2) discrete meaningful experience – the reflective glance directed at experience from a subsequent vantage point

As the individual faces an act, the immediate conscious motive is a prospective expectation, a 'let's go' reaction. This is the 'in-order-to' motive. The 'in-order-to' motive is an immediately conscious experience, and explains to the individual the meaning of an act. On the other hand, at each moment in the course of an action, and well after its completion, the individual will always take a backward look and relate the act to the past. This is the 'because' motive. The retrospective 'because' motive varies according to the vantage point from which the individual tries to relate the action to past experiences. Therefore, the meaning does not lie in the 'in order to' motive, but in the 'because' motive. An experience will only have meaning to an individual if it has been reflected on after the event, in the context of its consequences. Not all experiences are meaningful because they are not reflected upon[298]. Schutz summarised this and stated that 'social things are only understandable if they can be reduced to human activities; and human activities are only made understandable by showing their in-order to and because motives' (p.13[355]). Thus, in this thesis, the experience of TKR may be better understood from a post-operative vantage point where the patient has had time to reflect upon its impact and consequences.

One of the main criticisms of the phenomenological approach is its aim to understand the consciousness of another individual. This is not possible as one cannot get inside another's head in order to perceive the world as they perceive it. Schutz was aware of this and advocated a method that involved a detailed analysis of everything that is taken for granted. Biases and judgements will be exposed and described in this process from both the researcher's and the researched points of view[298]. It is, thus, important for the researcher to become immersed in the world of their subjects, without bringing their preconceptions into the interaction, so that a full understanding of the life of the other is explored.

***Symbolic interactionism***

Symbolic interactionism is defined as a theoretical framework based on the assumption that society involves interaction by which individuals actively construct reality in everyday life[356]. Blumer (1969) identified three principles associated with symbolic interactionism: 1) participants' actions are based on the meanings which certain objects have for them; 2) the participants attribute meaning to objects, through symbols; and 3) meaning attribution is the result of social interaction[357]. Thus, "symbols" are the basis of social life. Individuals and societies develop through people's interaction through symbols, and individuals develop a sense of themselves as they learn to use these symbols. Individuals also develop a sense of themselves as they learn to see themselves the way they believe others see them. Symbols can take the form of language, signs, gestures, or anything else from which meanings can be constructed[358].

For example, the white coat is a universal symbol of the medical profession. This colour, representing purity, is a visual reminder of the clinician's commitment to do no harm. White also represents goodness and conveys cleanliness and connotes a purging of infection. Furthermore, the white coat symbolises seriousness of purpose. It communicates the clinician's medical intent and serves as a symbolic barrier that maintains the professional distance between clinician and patient[359].

Blumer helped to promote the work of George Herbert Mead, who was one of the first to employ symbolic interactionism as an approach to qualitative research. Mead's view of the social world, and the heart of symbolic interactionism, is concerned with the inner experiences of the individual and how the self emerges from the social process[357]. He asserted that the self develops in childhood through the interactions with significant others, such as family, friends, and teachers. Although Mead conceded that there are

instinctual, unreflective human behaviours, he maintained that a human being has a self and, therefore, a person can be the object of his or her own actions. In other words, individuals can act toward themselves just as they might act toward others.

An important feature of symbolic interactionism is that it is grounded in the empirical world of the participants. Thus, if the patient's experience of arthritis and TKR is to be understood in terms of self perception, beliefs, values, and actions, symbolic interactionism may be a useful framework for allowing the researcher to get close to the phenomenon under study so that its forms and processes can be observed. Since interactions are constructed by those engaged in them, it is vital their perspectives, and the meanings they attach to them, are understood. Woods (1992) referred to this as 'learning the language of the participants, with all its nuances, gestures, actions, appearances' (p.355[358]), which convey meaning to others. Symbolic interactionism explores the ways members define, interpret and act upon situations and symbols in relation to the self, the role of the other, and one another in time.

These theoretical approaches have been criticised as they place little emphasis on empirical methods. However, the 'grounded theory' method provided a specific method for theory development *and* verification.

***Grounded theory***

The 'grounded theory' method, introduced by Glaser and Strauss in 1967, was developed to correct the imbalance, as they described it, created by an over-emphasis on verification of theory in sociology research[360]. They emphasised the need to focus upon the generation of theory. Their work was derived from phenomenology, but is concerned particularly with empirical work. They provide an initial definition of grounded theory. They state that it is a theory that will:

> *... fit the situation being researched and work when put into use. By fit we mean that the categories must be readily (not forcibly) applicable to and indicated by the data under study; by work we mean that they must be meaningfully relevant and be able to explain the behaviour under study. (p.3[360])*

The principal aim of grounded theory is the generation of theory, to be achieved in the absence of an *a priori* conceptual framework or hypothesis. Thus, the position adopted is not to begin with theory and then set out to test it, but to begin with an area of inquiry and allow whatever is theoretically relevant to emerge[361]. The emphasis in grounded theory is on participants' own understanding and the meaning they give to experiences.

Consequently, a great deal of data is generated which initially tends to be relatively unstructured, rich and complex. The intent of grounded theory is to provide the researcher with a way of systematically interpreting, unravelling and organising this type of data. It provides a set of data handling strategies including: generation of low-level categories, constant comparison, theoretical sampling and the search for deviant cases.

The method of constant comparative analysis refers to the process of repeatedly and methodically comparing data codes for variety in meaning, and this allows the generation of more abstract conceptual categories[360]. These categories then form the building blocks of eventual theory development. Hence, the theory is described as 'grounded' because it will be generated on the basis of the data. Another tenet of grounded theory is the principle of 'theoretical sampling'[360]. This states that data collection and analysis are not sequential. Rather, an iterative process takes place in which the data obtained shape further data collection and analysis - theory is 'discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon' (p.23)[361]. The sampling continues until theoretical saturation[360] is achieved – until new data are showing no new theoretical elements but rather are confirming what has already been found. The search for disconfirming evidence (negative or deviant cases) is an also important aspect of grounded theory as the contrasts that emerge should give a greater breadth and strength to the theory[362].

### Summary

The methodology of the empirical research of this study drew on many of the principles of the different approaches described above. It was based in phenomenology, as the meanings individuals attach to their behaviour were explored. In addition, aspects of symbolic interactionism may be relevant with reference to the clinical symbols surrounding the individual in the hospital. Particular components of the grounded theory approach were also employed in this study.

## Empirical design and methods

Qualitative research involves the studied use and collection of a variety of empirical materials – participant observation, focus groups and interviews – that will increase understanding of particular phenomena[363]. Qualitative methods call for 'thick', rich

descriptions of processes and are concerned with the meanings which participants attribute to social interactions and situations[364]. A qualitative approach was used for this study, as the aim was to gain a better understanding of informants' experiences of arthritis and TKR. The method of in-depth interviewing, using a semi-structured check-list of topics, was a practical choice in order to elicit these experiences. It was chosen rather than using a questionnaire or structured interview so that the informants' experiences would not be restricted and limited to fixed choice responses or pre-determined variables. The next section will describe the method of data collection, the sampling strategy used and the recruitment of the informants.

**Interviews**

Interviews in qualitative research may be structured, unstructured or semi-structured. In a structured interview, the researcher asks numerous individuals the same questions in a precise manner, offering each individual the same set of possible responses. In contrast, unstructured interviews are equivalent to guided everyday conversations, where the researcher has one or more topic areas that are probed, whenever the opportunity arises[365]. Semi-structured interviews are used more often in the context of health care, and are conducted on the basis of a loose structure, consisting of open-ended questions that define an area to be explored[366]. The aim of the interview is to discover the informant's own framework of meanings, and the research task is to allow the informant to expose his or her way of seeing things, without imposing the preconceptions of the researcher[367]. The informants are encouraged to express their views at length and in their own terms. Unlike quantitative interviews, based on highly structured questionnaires, the order in which questions are asked will vary, as will the questions designed to probe the informants' meanings. It is important that the interview maintains a conversational tone, despite the use of a guide. The interviewer must be flexible in following the informant into areas and topics pertinent to the research but not included in the interview guide[368]. However, the researcher needs to maintain control of the interview. Patton provided three strategies for maintaining control: knowing the purpose of the interview, asking the right questions to get the information needed, and giving appropriate verbal and non-verbal feedback[369].

In-depth interviewers usually start with questions that the informant can answer easily and then proceed to more difficult or sensitive topics[366]. Rapport should be established between interviewer and informant to create an atmosphere where the informant feels

comfortable in sharing his or her beliefs, opinions and attitudes[351,368]. In establishing rapport the interviewer should explain what he or she is planning to do, explain any equipment that will be used, and obtain informed consent[368]. The interviews are often tape recorded so that they can be transcribed for subsequent analysis[370]. Field-notes are also kept relating to the circumstances in which the interview took place.

In-depth interviews require considerable skill on the part of the interviewer. Whyte devised a six point scale to help novice researchers analyse their own interviewing technique[371]: 1) to make encouraging noises (the least directive technique); 2) to reflect on remarks made by the informant; 3) to probe on the last remark by the informant; 4) to probe an idea preceding the last remark by the informant; 5) to probe an idea expressed earlier in the interview; and 6) to introduce a new topic (the most directive technique). All six of these techniques may be required to encourage the informant to speak openly and freely about the relevant topic. Common pitfalls for the interviewer include outside interruptions, competing distractions, stage fright, awkward questions, jumping from one subject to another and the temptation to counsel interviewees[372].

The advantages of interviews compared with questionnaire surveys or structured interviews are that more complex issues can be probed, answers can be clarified and sensitive information can be explored[373]. They also provide a method for collecting data that allows the researcher to access an informant's own interpretation of a situation. The disadvantage is that the collection of data is time consuming.

## Sampling

Qualitative research uses non-probability sampling methods[362], as the aim is to increase the insight into social phenomena[373], rather than produce statistically generalisable findings[374]. Although there are various sampling strategies within qualitative research[375], they typically focus on relatively small samples of people, who either possess characteristics or live in the circumstances under study[376]. As Blumer (1979) (cited in Popay, 1998) has suggested:

> *'a half dozen individuals with such knowledge constitute a far better 'representative sample' than a thousand individuals who may be involved in the action that is being formed but who are not knowledgeable about that information'. (p.347[377])*

Theoretical or purposive sampling, an approach used in grounded theory, is where the research guides the sampling and data collection procedure[360]. On the basis of theoretical understanding, the researcher determines what factors might affect

variability in the observations and then endeavours to draw the sample in a way that maximises the variability. Thus, maximum variation techniques aim to produce as many categories as possible in order to 'detail the many specifics that give the context its unique flavour' (p.201[374]). It also challenges the investigator's preconceived (and developing) understandings of the phenomena under study and identifies important common patterns that cut across cases[375]. According to Popay, 'the hallmark of good qualitative methodology is its variability rather than its standardisation' (p.346[377]).

In this study, the aim was to gain an understanding of the experience of a TKR. Individuals were purposefully selected from the TKR waiting lists[375]. Maximum variation was attempted by using three consultants' waiting lists, and including a broad range of informants, including old/young, men/women.

## Recruitment

### *Selection of individuals for interview*

Interviews were conducted with individuals who were on the waiting list for a TKR. Permission to access these individuals was given in writing by three orthopaedic surgeons. Once ethics committee approval had been obtained, the consultants' secretary provided the TKR waiting lists for each consultant, and flagged the individuals who had approximately 3 to 4 months to wait before their operation. From the information on the waiting list card, I recorded the following: the informant's name and address, date of birth, GP name and address, the date placed on waiting list, the hospital number and the consultant. Information about previous TKRs and other co-morbidities were not available. I informed the secretary which individuals I had noted down and said that I would telephone her when their consent had been received. A flow chart outlining full selection stages of the sample is provided in Appendix I.

Selected informants were contacted by post with a letter signed by their respective consultant introducing the study. Also enclosed was an information sheet signed by me, which described what the interview would involve, what I was interested in talking to them about and also assured them of confidentiality. A reply slip, attached to the information sheet, gave the informant one of three options to choose from: 1) would they be willing to be contacted by telephone to arrange a time for interview; 2) would they like more information before they gave their consent and; 3) gave them the opportunity to refuse participation in the study. A copy of the consultant's letter, the information

sheet and reply slip is in Appendix II. The informant was asked to return this reply slip with their response in the enclosed envelope. Once the reply had been received, the consenting informants were contacted by telephone to arrange a time and date to meet. This also gave them the opportunity to ask any questions and enquire about the study. After consent was given, I telephoned the consultants' secretary at the hospital to give her the names of these informants, and she marked them down to have their operation in approximately three months time.

## Method of data collection

### *Pre-operation interviews*

Before the interview commenced, each informant was asked if they were happy for the interview to be tape-recorded. They were also asked to complete and sign a consent form (see Appendix III), which assured confidentiality and reminded them that they could withdraw from the study at any time without having to give a reason, and also without affecting their future medical care.

A semi-structured interview schedule was used as the main source of data collection. This was essentially a list of topics to be covered during the interview, although this was not adhered to in strict order. The main aim was to get the informant to speak freely about their experiences of arthritis and their expectations and thoughts about the approaching operation. Therefore, the interview was led mostly by the informants, and the topic guide was used to ensure that particular areas of interest were covered. A copy of the interview guide (pre and post operation) is in Appendix IV.

The interview started with a brief introduction to the study. In the majority of interviews two questionnaires, the WOMAC (disease-specific questionnaire for lower limbs)[314] and the SF-36 (generic health questionnaire)[319], were given to the informants to complete. The aim was to examine the face validity of these questionnaires (the results are not included in this thesis as they will be published separately).

The completion of the questionnaires also acted as an 'ice breaker'[378] and gave the informants a chance to relax and discuss some basic issues about their symptoms and disabilities. The interview then progressed to questions to explore a number of issues: the informant's experience of their arthritis, the impact of their arthritis on daily life, their contacts with health and social services and their expectations of the TKR. During the research, the interview schedule was adapted to allow for emerging themes. At the

end of each interview, I asked the informants if they would be willing for me to interview them again approximately six months after their operation: all agreed.

***Post-operation interviews***

A sample of ten pre-operation informants was chosen for a follow-up interview, six months after their operation. Informants were chosen to obtain an equitable ratio of males and females, and age. The ten informants were sent a letter introducing the study again and informed them that I was interested in hearing about their experience of the operation, hospital and recovery process. The letter stated that I would contact them again within the next week by telephone to arrange a time and date for the post-operation interview (see Appendix V).

Each post-operation interview began by asking the informant to describe what had happened to them since our last meeting. Specific questions about their expectations, satisfaction with treatment and the recovery process were then discussed in more detail.

After each pre- and post-operation interview, field notes were made on a contact summary form[376] (see Appendix VI). This included information about the informants, the interview setting, the time taken, and any disruptions that occurred during the interview. They also included brief details of the main issues discussed, a summary of information that was not collected on tape and any new or exciting target questions that arose from the interview.

## Data analysis

Analysis drew on grounded theory procedures and used the method of constant comparison[360]. Within this study, data collection (semi-structured interviews) and data analysis continued concurrently. This complex iterative process enables the researcher to refine the interview questions, develop hypotheses, pursue emerging themes, and search for deviant/negative cases[379].

***Transcriptions***

To ensure accuracy and detail of information[380], all interviews were tape recorded using a high quality tape recorder with external microphone and high quality cassettes. I fully transcribed the recorded data (an accurate recording of the words spoken, including interruptions, pauses and laughter) as soon as possible after the interview, in order to remember nuances, sarcasm, and intonation in the interview. Although the essence of

the interview should not be edited, it was thought legitimate to remove the 'umms' and the length of pauses, unless they were important for the meaning of what was being said[381]. Close attention was made to the punctuation of the transcripts[381], by checking each passage with the audiotape to ensure that commas and periods (indicating pauses and breaks in the speech) were correctly used to maintain the informant's expression. At the beginning of each interview, the informants were promised confidentiality for their participation. Thus, all interviews were anonymised, with letters substituting informants' names, and hospitals' and doctors' names being replaced by numbers. The transcripts were checked to ensure accuracy and to permit familiarity with the data.

*Coding*

After transcription, the Word transcripts were transferred into a qualitative analysis software package (Atlas.ti 4.5[382]) for coding. This computer software enables quick coding of text with easy visualisation of the coding transcripts: one side of the screen is the transcript and the other side, divided by a margin, is the coding section. Codes are created by a simple 'drag and paste' action connecting a particular code to a section of the transcript. The potential benefit of the computer package is to help with the more laborious side of textual analysis and to enable efficient organisation and access of the data and coding [383]. Its also ensures that all segments of the data in the relevant category are made readily available to the researcher[367]. However, this is only the initial stage in qualitative analysis. 'The essential tasks of studying text, recognising and refining concepts and coding data are inescapably the work of researcher' (p.122[384]). No package is capable of perceiving a link or defining an appropriate structure for analysis[379]. Thus, once coding had been completed, all the information was transferred back to a Word processing package for further in-depth analysis.

The initial step taken in analysis, as recommended by Strauss and Corbin (1998), was 'open coding' (also known as 'first level coding'[361]). Coding 'represents the operations by which data are broken down, conceptualised, and put back together in new ways. It is the central process by which theories are built from data' (p.57[361]). The idea is to open up the theoretical possibilities in the data and attach meaning to the chunks of data[348]. The transcripts were inspected line by line: single words, phrases and sentences were taken as the unit of analysis and given codes relating to their meaning and characteristics. A 'coding template' was developed after the first set of four interviews was conducted. These codes were largely descriptive at this stage and were intended to

have a wide scope to allow for variation within each category. The coding template continued to evolve as new information was collected. For example, it became apparent that the informants attached many possible causes to their OA; one main cause and other contributory causes. Thus, the coding structure had to be separated into these codes. This process reflected the continuous cycle of data collection and analysis, as stated by the constant comparative methods of grounded theory[360].

***Descriptive accounts***

The next step in analysis was to examine the relationships between themes and categories. Five descriptive accounts of the pre-operation interviews were written using data from 5 groups of 4 informants, and one group of 5. The aim of this was to discuss similarities and differences for each theme between the informants. This developed the descriptive coding into a more interpretative analysis. All the responses falling under each code were included. The data were also examined to check for patterns between the themes that cut across cases. A matrix for each theme was developed to assist the identification of links and themes.

Whilst refining and defining conceptual categories, I began to develop ideas or hypotheses about how the different concepts related to one another. Making sense of the links between concepts is known as 'axial coding' or 'second level coding' and it is an important part of theory building. According to Strauss and Corbin (1998) the purpose of axial coding is to begin the process of re-assembling the data fractured during open coding[361]. As with the open coding, axial coding involves constant comparison of concepts and the asking of different 'why' and 'how' questions.

***Longitudinal analysis***

Ten of the informants in this study were interviewed before and after the TKR. Analysis of the transcripts of those informants who had both a pre- and post-operation interview examined the links between pre-operation views of the TKR and subsequent judgements about the outcomes of the operation. A case study for each individual was written. In order to ensure reliability and validity of the case studies, my advisors independently assessed four of the informants' pre-and post interviews and developed case studies. These were then discussed. The case studies were then examined for similarities and differences in the informants' experiences of the TKR. A matrix was developed to aid

this process. In longitudinal case study analysis, the researcher usually aims at gaining the most complete possible view on the subject by regarding it as a holistic entity.

## Criteria for evaluating qualitative research

Recent guidelines and criteria for the assessment of qualitative research have been developed, in response to the increasing focus on research quality[377,385-387]. However, there is considerable debate over what constitutes good interpretation in qualitative research, and this reflects the different approaches taken[347]. There are those that argue that no criteria can judge qualitative research as it this is antithetical to the nature of this research[385]. In this 'relativist' position, all 'criteria are doubtful and none can be privileged' (p.343[377]). Others state that the same quantitative criteria (validity, reliability, generalisability) should be applied to qualitative research, as there is nothing so unique about qualitative research that demands a special set of criteria[388]. Popay *et al* stated that if this approach is adopted, 'then at best qualitative research will always be seen as inferior to quantitative. At worst, there is a danger that poor quality qualitative research, which meets criteria inappropriate for the assessment of such evidence, will be privileged' (p.343[377]). The third perspective states that a set of criteria unique to qualitative research should be developed because it represents 'an alternative paradigm to quantitative social research'[385]. In this perspective, the criteria for qualitative research require tailoring to the particular features of work. Thus, while the quantitative paradigm seeks trustworthiness through, for example, randomisation and probabilistic sampling, the qualitative paradigm seeks the same ends through different methods, which are better suited to a human subject matter, for example, purposive sampling. In this way, 'both quantitative and qualitative methods are equally 'scientific' and 'rigorous' but via different routes' (p.176[389]).

Stiles (1993) suggested the traditional notions of reliability and validity can be translated into the notions of 'procedural trustworthiness' and 'interpretation trustworthiness', respectively. Whilst the former refers to the trustworthiness of the data and observations gathered, the latter refers to the trustworthiness of the interpretations drawn. By following established guidelines on methodological procedures and report presentation, the trustworthiness of qualitative research is improved[390]. These recommendations were also made by Lincoln and Guba (1985), who stated that conceptions of 'credibility', 'transferability', 'dependability' and 'confirmability' were more appropriate for assessing qualitative research[374]. 'Credibility' refers to the 'truth

value' of the data collected. It ensures that the multiple constructions held by the informants are represented adequately and that these 'reconstructions' are credible to the original informants. The emergent theory of naturalistic inquiry is dependent on a specific context and interactive dynamics, necessarily lowering the possibility and desirability of a focus on external validity, as compared with positivistic inquiry[374]. Instead, naturalistic inquiry depends on a presentation of 'solid descriptive data', or 'thick description'[375] to improve an analysis' 'transferability'.

According to Lincoln and Guba (1985), both 'dependability' and 'confirmability' can be determined through one "properly managed" audit. To establish dependability, the researcher examines the process by which the various stages of the study, including analytic techniques, were conducted. The researcher determines whether this process was applicable to the research undertaken and whether it was applied consistently[374]. To illustrate confirmability, a record of the inquiry process, as well as copies of all taped interviews and discussions, notes from interviews and discussions, and hard copies of all transcriptions have to be maintained. These records are available upon request from the researcher. This ensures that the emphasis is not on the investigator, but on the data themselves.

Hammersley suggested two criteria for judging qualitative findings – truth (validity) and relevance[385]. An account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise. 'Validity' is interpreted in terms of selective representations of reality, with the amount and nature of the evidence that is necessary depending on the type of claim involved, and on judgements about its plausibility, credibility and centrality. 'Relevance' concerns the importance of the research topic and the contribution to our knowledge made by the findings of the study.

Whatever the criteria used, it is acknowledged, in general, that all parts of a qualitative research project must be conducted in ways that maintain the scientific rigour of the enterprise. The main premise is that the researcher should be honest about their theoretical perspective from the outset, and the research should be conducted in an explicit and systematic way in relation to design, data collection, analysis and interpretation[373]. By providing such an account, the reader is in a better position to judge the logic, adequacy and credibility of the method and analysis.

*Investigator triangulation*

To ensure the reliability of the interview, the first interview transcript was read by my advisors who gave their comments and recommended the development of certain areas. They also independently assessed the coding template. This process is also referred to as 'confirmability'[374] or 'investigator triangulation'[391]. Each coded two pre-operation and two post-operation transcripts. We compared codes assigned to segments of text by going through the transcript line by line. The comparison of agreement between our codes confirmed a good level of reproducibility, although there were some discrepancies. These tended to reflect the particular interests and areas of expertise of the coder. For example, one advisor, a social scientist with in-depth knowledge of qualitative analysis coded the interviews and examined the links between previous research on perceptions and experiences of inflammatory arthropathies, particularly the importance of pain and mobility. The other advisor, a consultant rheumatologist, had little experience of qualitative analysis and was primarily interested in understanding the dimensions of outcome (function, pain, stiffness) and to understand the experience of being in hospital (patients' perspective of assault, and also issues of dignity, dependency and communication). Often, codes were very similar, using sometimes identical terms and at other times forms of words, that after short discussion, we were able to agree meant the same things. For example, a segment with the informant discussing the straightening of the leg as part of the operation was identified in three ways, either as 'bending', 'straight leg' or 'flexion'. Some of the time, particular individuals offered additional codes that the others had not identified (gaps). We discussed each of these 'gaps', some of which appeared to be more significant than others. For example, one coder picked up a thread running through the interview in which the informant compared hips with knees. Another example centred on a section where the informant discussed a range of issues about the hospital stay; it was coded as 'patient expectations' by myself and one advisor, but as 'clinicians do not communicate' by another. These discrepancies were discussed and resolved, either by reference to the original transcripts or the acknowledgement that during the 'second level' coding, these issues would be taken into account (for example, in preparing the descriptive account or on a subsequent reading of the transcripts to refine the coding framework). In addition, the pre- and post- operation descriptive accounts were read by one of my advisors, we

discussed them and made amendments to the interview schedule and interpretation as appropriate.

### *Triangulation*

Triangulation (obtaining evidence from as diverse and independent a range of sources as possible)[391,392] is said to safeguard validity in qualitative research[376]. It is thought that by cross-checking observations amongst divergent data sources, apparent differences may eventually resolve themselves and a favoured interpretation may be constructed that coheres with all the divergent data sources[389]. However, Hammersley and Atkinson have pointed out: 'one should not adopt a naively "optimistic" view that the aggregation of data from different sources will unproblematically add up to produce a more complete picture' (p.232[351]). They state that different methods of data collection sometimes produce different results and 'rarely does the inaccuracy of one approach to the data complement the accuracy's of another' (p.35[393]).

In this study, the main method of data collection was semi-structured interviews. However, before the interviews were conducted, I observed a number of patient hospital consultations (the consultant being one of my advisors). Although this does not constitute using methods of triangulation (as I have not combined the results from the observation and in-depth interviews together), it helped me to develop an understanding of the patients' experience of OA and how they present themselves in a hospital consultation. It also gave me the opportunity to talk to patients after their consultation.

### *Respondent validation*

The credibility or the validity of the study results is reportedly enhanced by obtaining the informants' reactions to the analysis, and these reactions can then be incorporated into a more complete analysis[374]. This is known as 'respondent validation'[394] or 'member checking'[374]. It has been described as:

> *The process of testing hypotheses, data, preliminary categories, and interpretation with members of the stake holding groups from whom the original constructions were collected. This is the single most crucial technique for establishing credibility.*(p.239[352])

It is thought that the informants will be able to confirm immediately the accuracy and validity of the study, be able to clarify points, and offer additional information to confirm the model further[395]. However, critics state that this strategy is inappropriate as

sometimes the results report on findings that are implicit in the setting; so even the participants themselves may not be aware of key features of what has happened to them and must themselves 'check out' the results[381]. Hammersley argued that respondent validation would not give a 'sound indication of truth' (p.65[385]) as there are multiple realities, and also the informants 'may feel that it is in their interests not to accept or admit certain truths or to accept falsehoods' (p.65[385]). For example, the research findings may be in conflict with the informant's self image and therefore, the inclusion of unflattering portrayals or details may not be approved of.

In addition, when adopting respondent validation, the social character of the relationship between researcher and interviewer is ignored and implies that it is the informant who has privileged access to the truth[385]. Fielding and Fielding (1986) stated that 'there is no reason to assume that members have privileged status as commentators on their actions...such feedback cannot be taken as direct validation of refutation of the observer's inferences. Rather such processes of so-called "validation" should be treated as yet another source of data and insight' (p.43[393]). Silverman, also shared this view and stated that 'respondent validation' was just another form of data and another view of reality[394]. Thus, in this study I did not give the informants the opportunity to discuss the analysis process. However, in the post-operation interviews, many of the informants reiterated a lot of the pre-operation information, confirming accuracy of their pre-operation accounts.

***Deviant cases***

A form of theory testing is the 'search for negative cases'[367]. This is a process where the researcher challenges his or her developing understanding by deliberately looking for instances that challenge or contradict emerging themes or theory. It is also a useful method in testing the robustness of the researcher's generalisations as it compels the researcher to examine critically his or her own interpretations. Thus, rather than permitting interpretation only for "typical" or "juicy" transcripts, this criterion requires a more balanced approach[396]. Researchers must, therefore, present transcripts that prove their points and others that do not, and also explain why this variability occurs[396]. 'To present material that is both consistent and inconsistent with the theoretic positions at hand injects a certain self-effacing discipline into the research effort' (p.481[396]). Throughout the analysis, I looked for negative cases and examined how the data differed.

### *Presentation of findings*

It is not feasible to present all the data collected to the reader[367]. This has led critics to state that qualitative researchers could select an unfair and unrepresentative collection of quotations[367]. To prevent this from occurring, the provision of one or more quotations in support of a particular theme or sub-theme is provided. This is a common form of confirmation, also known as 'source triangulation'. Also when quoting an informant, an identifier is added so that all quotes can be traced back to the original transcripts.

Counting is also useful to indicate how significant and comprehensive a theme is[376,394]. It provides a means of surveying the whole of the data and provides evidence for the researcher's impressions of the data. The selection of quotations was based on three premises: they had to be representative of the theme, they had to be articulate/concise, and to avoid excessive selectivity in reporting data, they had to represent an informant who had not been selected often elsewhere in the analysis. The quotations have been 'cleaned' only to the extent that utterances such as "umms" and "ahhs" have been omitted if they did not affect the meaning of the quotations. This allows for easier reading.

### *Reflexivity*

Few would dispute that qualitative methods invariably involve the interaction between the researcher and the data[397]. In qualitative inquiry, the researcher is the research "instrument"[351]. Hammersley stated that 'there is no way in which we can escape the social world in order to study it' (p.17[351]). Some researchers state that assessment should be made of the way in which the people studied may have tailored their behaviour for the researcher, and the researchers' own preconceptions should be described as honestly as possible[367]. Thus, an awareness of contextual details, such as the interview setting and the interaction between the interviewer and the informant, is important[374]. This is known as 'reflexivity'. Some state that if these processes are not carried out, the interpretive process collapses and the researcher will perceive a mirror image of hopes/fears and not the social reality[398]. Counter-arguments posit that it is the reflexivity and the researcher's creativity within this reflexivity that makes qualitative research most valuable[397]. Turner (1981) said that it 'directs the researcher immediately to the creative core of the research process, and facilitates the direct application of both the intellect and the imagination to the demanding process of interpreting research data' (p.277[399]). In addition, by including or even exploiting the researcher's role within the

research focus, researchers can 'produce accounts of the social world and justify them without placing reliance on futile appeals to empiricism, or either positivist or naturalist varieties' (p.21[351]). Stiles stated that researchers cannot eliminate their views and preconceptions, but they can work to make them permeable, via triangulation, the search for negative cases, and repeatedly seeking consensus through peer debriefing, as described above[390]. Miles and Huberman also suggest that one way to avoid the researcher effect is to ensure that participants are aware of what the purpose of the research is, why you are there, what you are studying, how you will be collecting information and what you will do with this information[376]. Thus, in qualitative research, how the researcher presents themselves to the informants should be clearly reported[384]. It has been suggested that the interviewer be perceived as neutral with regard to the subject matter of an interview[400]: this is especially important when informants are encouraged to speak openly about features of their health care[384].

### *Author characteristics*

I was born in Scotland in 1972 and moved to England in 1980. We had a close family network as my mother's parents lived nearby. They were both active in their community and my grandmother organised many 'over 60's' social groups. Neither they nor my other grandparents (to my knowledge) suffered from OA or any other chronic illnesses, which disrupted their lives. As a result of having active and healthy grandparents, my view of old age has always been favourable and represents a positive, enjoyable period of life. In addition, as neither I nor anyone else in my immediate family has experienced OA or chronic joint pain, my view of OA was limited. In accordance with the typical view of OA, I considered the condition to be the result of age and joint 'wear and tear'. I was aware of TKR as being a treatment for OA that involved major surgery but had never known anyone or spoken to anyone about his or her experience.

Most of my knowledge of OA derived from a professional background. Previous to the start of this PhD, I worked as a health services research assistant in the Department of Social Medicine at Bristol University. During that time, I worked on a variety of quantitative and qualitative methods, ranging from a randomised controlled trial to semi-structured interviews with people with OA. These interviews were structured and were primarily focussed on the individuals' expectations about their hospital consultation. However, during the interviews, the individuals would often discuss their

OA symptoms and describe the pain and disability associated with this condition. It was also during this period that I became very aware of the limitations of using a quantitative methodology to elicit the views and experiences of those with a chronic illness. For example, while I conducted the interviewer administered questionnaires it was apparent that the answers the individuals provided on the questionnaires were often contradictory and conflicting with what they were actually saying to me in the interview procedure. As a consequence this led me to propose a qualitative methodology to investigate in-depth the experience of OA and a TKR. In this study, a notebook was used to outline my 'reflexive' thoughts throughout research process.

In the following chapters, the data gathered through the in-depth interviews will be presented. Chapter five documents the profile of the informants. Chapters six and seven present the results, which are arranged according to the major themes that emerged from the interview data.

# CHAPTER 5: PROFILE OF INFORMANTS

## Introduction

Having described the methods that were used to collect and analyse the data in the previous chapter, the results are now presented. This chapter will detail the characteristics of the informants in this study.

## Characteristics of informants

The characteristics of the 25 informants are outlined in Table 5.1 and Table 5.2. Fourteen were female and 11 were male. Informants were aged between 40 and 84, with five informants aged between 40 and 59, ten informants aged between 60 and 69, and ten informants aged between 70 and 84. The age range was different for the two sexes, with more older females (55 to 84) and more younger males (40 to 80). The age of the informants was reflected in their occupational status. At the time of pre-operation interview, 21 of the informants were retired, three were on disability allowance and one was in full-time employment. Occupations varied from domestic cleaners to managers: nineteen informants had manual and six non-manual occupations.

As can be seen in Table 5.1, sixteen of the informants were married and nine were single. All but one of the informants (who lived in a residential home) lived in their own home. Sixteen of the informants had had previous operations on either their knee or hip, ten being a total joint replacement. No one in the sample had had a revision operation or was waiting for one. One informant had rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE), and the remainder had OA. Three different consultants were used to recruit patients in this study. Twenty of the informants were recruited from one consultant's list, four from the second consultant, and one from the third consultant.

## Pre-operation interviews

Pre-operation interviews were conducted between May 1999 and July 2000. Details of each pre-operation interview (the setting, its length, and brief comments on the conduct of the interview) are given in Appendix VII. In eleven of the interviews, the informants' spouse was present, although not throughout the whole duration of the interview. In all but three of these interviews, the spouses only interrupted the flow of the interview periodically, and were in general quiet. Settings were generally comfortable with

minimal background noise. Pre-operation interviews took between one hour and two and a half hours, with eight of the interviews lasting two hours or longer.

All interviews were generally relaxed, although some of the informants did appear nervous. In two of the interviews, the informants became upset, both about their OA condition and about the death of a close family member. Both informants, however, managed to regain their composure without stopping the recording. All informants said they were pleased to be able to talk to someone about their condition and indicated that the experience was rewarding and cathartic.

All but one of the informants (who had the TKR two weeks after the pre-operation interview) did not know of their operation date at the pre-operation interview. The time difference between the pre-operation interview and the actual operation varied from two weeks to 10 months. The majority of informants (N= 15) were operated on two to four months after the pre-operation interview, whereas three were operated on either two weeks or a month later, and one informant was operated on ten months later. Of the remaining informants, two had cancelled their TKR, one stating that he had just started to use a knee brace which helped his knee, the other stating that she did not want the TKR. One patient had private surgery due to the long NHS waiting list time. Another informant went in for her TKR pre-assessment, but was told by the consultant that he would operate on her foot first, as he believed this was more urgent than the TKR. Two of the informants were referred to the cardiology department with co-morbidities after their pre-assessment appointment. The follow up interview occurred between five months and six months 15 days (mean 5 months 25 days) after the operation.

## Post-operation interviews

Post-operation interviews were conducted between February 2000 and February 2001. These informants are indicated in Table 5.1 and Table 5.2 by a star (✱). Of the ten post-operation informants interviewed, six were female and four were male and their age ranged from 40 to 81. Seven of the informants were retired, and three were on disability allowance.

As can be seen in Table 5.1 and 5.2, five of the post-operation informants were married and living with their spouses, and the remaining five were either single, divorced or widowed. All post-operation informants lived in their own home. Seven of the post-

operation informants had had previous operations on either their knee or hip, three being a total joint replacement. Nine of the ten post-operation informants were from the same consultant's list.

The characteristics of the interview for the post-operation interviews are detailed in the Appendix VIII. The post-operation interviews were all conducted in the informant's homes and the conditions were generally comfortable. In one interview, the informant's child interrupted the interview but these disruptions tended to be short and easily dealt with. For one interview, the tape recorder failed to work, so field notes were written immediately after the interview. Interviews with the post-operation informants took between one hour and two hours 10 minutes.

*Table 5.1 Basic characteristics of female informants*

| Patient ID | Sex | Age | Occupation | Family | Previous operations |
|---|---|---|---|---|---|
| Mrs A | Female | 55 | Retired office worker | Married, lives with husband | TKR on left knee 1 year ago. Club feet |
| Mrs B ✸ | Female | 62 | Retired shop worker | Married, lives with husband | None |
| Mrs C | Female | 63 | Retired cleaner | Married, lives with husband | None |
| Miss D ✸ | Female | 64 | Retired social worker | Single, lives with brother | None |
| Mrs E ✸ | Female | 64 | Retired cleaner | Married, lives with husband | None |
| Mrs F | Female | 65 | Retired office worker/waitress | Married, lives with husband | TKR 1 year ago |
| Mrs G | Female | 68 | Retired office worker | Married, lives with husband | TKR 1 year ago. RA and SLE patient |
| Mrs H | Female | 68 | Retired factory worker | Married, lives with husband | None |
| Mrs I | Female | 69 | Retired nurse | Divorced, lives in residential home | None |
| Mrs J ✸ | Female | 71 | Retired nurse | Married, lives with husband | TKR on left knee 6 years ago |
| Mrs K | Female | 75 | Retired cleaner | Married, lives with husband | THR 10 years ago. TKR on right knee 1 year ago |
| Mrs L ✸ | Female | 80 | Retired office worker/waitress | Widower, lives alone | THR 5 years ago |
| Mrs M ✸ | Female | 81 | Retired office worker | Widower, lives alone | TKR on left knee 4 years ago |
| Mrs N | Female | 84 | Retired office worker | Widower, lives alone | None |

✸ - *Indicates those informants who also had a post-operation interview.*

*Table 5.2 Basic characteristics of male informants*

| Patient ID | Sex | Age | Occupation | Family | Previous operations |
|---|---|---|---|---|---|
| Mr O ✸ | Male | 40 | Project housing manager - on disability allowance | Married, lives with wife and four children | Total cartilage removal 21 years ago |
| Mr P ✸ | Male | 48 | Factory worker – on disability allowance | Single, lives alone, father recently died | Total cartilage removal 16 years ago |
| Mr Q | Male | 51 | Factory worker | Married, lives with wife and two children | Total cartilage removal 23 years ago |
| Mr R | Male | 59 | Retired office manager. Ex-professional footballer | Married, lives with wife | Total cartilage removal 35 years ago |
| Mr S ✸ | Male | 64 | Factory worker – on disability allowance | Married, lives with wife | Knee operation 12 years ago |
| Mr T ✸ | Male | 66 | Retired post man | Divorced, lives alone | Knee operation 25 years ago |
| Mr U | Male | 70 | Retired manager | Married, lives with wife | THR 11 years ago |
| Mr V | Male | 74 | Retired office worker | Married, lives with disabled wife | TKR 21 years ago |
| Mr W | Male | 78 | Retired factory worker | Widower, lives alone | None |
| Mr X | Male | 78 | Retired office worker | Married, lives with wife | THR 4 years ago, Total cartilage removal 50 years ago |
| Mr Y | Male | 80 | Retired office worker | Widower, lives alone | Total cartilage removal 50 years ago |

✸ - *Indicates those informants who also had a post-operation interview.*

# CHAPTER 6: LIVING WITH OSTEOARTHRITIS AND PATHWAY TO SURGERY

## Introduction

This chapter presents the results from the pre-operation interview in two sections. The first section details the experiences of those living with OA. From the informant's perspective, it covers aspects of the perceived cause and nature of OA, and the pain and disability experienced. The second section presents the results relating to the process of referral and listing for surgery. The informants' decisions to seek or not seek help are described, along with their perceived view of the GPs' reasons for referral, and surgeons' decisions for listing for surgery.

## Cause of Osteoarthritis

The informants all had views as to the cause of their OA. Each expressed a general view in addition to a specific event, which they believed caused or exacerbated their condition. These views suggest that informants try to come to terms with their OA and make sense of it, in the context of their own lives.

The majority of informants (20) believed the general cause of their knee OA was due to 'wear and tear':

> *Mrs C: I have had wear and tear for years and years and years.. I did school cleaning for over 15 years.. carrying Hoovers up and down the stairs and doing school work, some of the machinery was heavy, it was hard work.. so I used to do school cleaning, sometimes I did office cleaning and then Saturdays I used to do holiday flat cleaning, so it has just worn out, completely worn out.* ***(63, married female, retired, no previous TKR)***

This wear and tear was thought to have been caused primarily by age-related damage (22), however, doing too many sports as a child (8), occupational damage (8), compensation of the weight from their other injured knee (4), physical stature (3) and being overweight (1) were also cited. Nine informants also referred to hereditary factors, and a smaller number of informants mentioned causes such as diet (2), a blood deficiency (RA informant), and even divine retribution (1):

> *Mr U: we used to laugh when my grandmother used to complain about pains all the way down her back of her legs and we used to, both*

*my sister and I, used to laugh because she said it was like 'red hot wires' being put down her legs, and we used to laugh and I sometimes think that we are probably being punished for laughing. I say to my sister sometimes, 'I wish to goodness we had never laughed at grandma'.. you know.. well it makes you feel like you have got it because of that... I feel as though I am being punished for my wickedness.* ***(70, married male, retired, previous hip replacements)***

Specific events discussed by the informants centred on accidental injury (banging knees/falling) (14), road traffic accidents (3) and two informants recalled incidents during World War II:

*Mr W: I was a gunner in the war, there were these big wagons called three tonners and we used to tow the guns along on them and when we were training, when they said 'action' we had to get out quick and jump off the tail board and the tail board is up here .. have you seen the big wagons.. we had to jump off there. Continually jumping off the tonners.. I never landed on two feet, I always fell on my left one, that's what I think it is.. jumping on my left leg.* ***(78, widowed male, retired, no previous knee operations)***

Six informants discussed specific sporting injuries and subsequent surgical operations. They were aware that the sports injury triggered their OA, but felt that the consequent cartilage removal operation exacerbated the progress of their OA:

*Mr O: When I was 19 I had total cartilage removal at hospital 2, apparently they don't do that operation anymore and I was even told later on by a consultant that, at the age I was, the consultant should never have done it.. he said that is basically what really set things rolling as fast as it was, was actually having the cartilage out, once that happened the osteoarthritis set in and then it just went down-hill from there.* ***(40, married male with family, on disability allowance, previous knee operations)***

One informant, although specifying a general and specific cause, also had his own theory about his OA. He described it as a disease that travelled through the bloodstream to the bones, and was comparable to leukaemia. He stated that arthritis had periods of dormancy and activity, and that once it was disturbed (for instance, by an injury) it became rampant:

*Mr S: it's a moving matter and it likes the human bone, it doesn't come out on the flesh, it's the bone so I think it just knaws it's way through the bone but when the body is damaged that's when it comes, it lies in the body dormant and then something disturbs it, accidents like I had and it completes itself, like leukaemia, that's the same.. the white cells eat the red ones, there's more white cells what there are red and that's the same with arthritis.. it will go as far as it can, I can feel it in*

*my shin to be honest, it travels you see down the blood stream, I think it is in the blood stream, couldn't travel no other way, it's in the blood stream and the blood flows through your veins and through the bone and well that's it... but like I told you once it is disturbed there is no stopping it, it completes it's course, it's rampant and it completes its course and there is nothing in this world you can do* ***(64, married male, retired, previous knee operations)***

## Perceptions of osteoarthritis

In general, although the informants (20) acknowledged that the OA affected their health and lives, they did not perceive themselves to be "ill". OA was portrayed as a 'wear and tear' condition that was expected in old age:

*Mr R: I wouldn't have thought so really cos I look upon it as a stage of your life you go through when you are getting older. I don't see it as an illness, it's just something that happens.* ***(59, married male, retired, previous knee operations)***

*Miss D: not an illness, it was just the injury or.. just old age as well I don't know. they say it's just a wear and tear thing.* ***(64, single female, retired, no previous TKR)***

Thus, they did not view OA as an illness but more as a physical disability:

*Mrs J: with a physical illness I mean like with cancer, that sort of physical illness, it's not like that sort of thing, is it? It's, well I don't know.. I've never sort of thought of it as an illness, I mean I've thought of it as a painful disability... So I don't know if you can describe that as an illness or what... I mean what I call as a physical illness is something like.. sort of a stomach problem or appendicitis or things like that and sort of..... affects inside.* ***(71, married female, retired, previous TKR)***

*Mrs H: I mean when you are ill you don't feel very well do you, well it don't get me like that.. no, not the flu or tonsillitis or anything, I would call that an illness but not this.* ***(68, married female, retired, no previous TKR)***

*Mr S: well an illness is like flu or chicken pox, mumps, colds, viruses and a disease is actual disease, it gets into the bone, if you want my personal opinion I don't think it will ever be cured, there's too much of it.. a disease they never cure... all I can think of with what I feel and what I know is classed as a disease.* ***(64, married male, retired, previous knee operations)***

This affected the way 12 informants dealt with their OA, as they tended to accept their condition and were willing to *'tolerate'* the symptoms:

*Mr R: you can accept it when you are say 55 or 60, oh yeah I can accept getting it at my age but for a kid of 20 that must be devastating I should think … yeah, time takes it toll.* ***(59, married male, retired, previous knee operations)***

*Mr U: well I don't consider this as sort of really an illness, it's just something I have to put up with.* ***(70, married male, retired, previous hip replacements)***

The five informants who did class OA as an illness, cited reasons such as the major impact that pain has on people's lives:

*Mrs K: a) I could say yes because of pain, b) not an illness that can take your life, not life threatening but because in the end it affects your health,…your mentality, how you can cope with it, what can be done to get you out of this pain?.. so in the long run how it affects you all the way round.. yes it could be an illness.. I am not saying a life threatening thing but you just think of people being in pain, not just for an hour, but 24 hours a day, and for 7 days a week, 52 in a year.. it is.. because as I said it can affect you mentally because you think 'oh how much more can I endure'.* ***(75, married female, retired, previous TKR and THR)***

Three of these five informants said they felt very depressed by their condition and tended to be negative about how they coped with their activities:

*Mrs K: because in the end it affects your mentality, 'how you can cope with it', 'what can be done to get you out of this pain', you just have to sit and you can't do nothing, so in the long run how it affects you all the way round.. yes it could be an illness.. being in pain, you think 'oh how much more can I endure'.* ***(75, married female, retired, previous TKR and THR)***

## Problem of recognition

A major difficulty experienced by informants was the problem of recognition of their pain and disability by others. Most (20) felt that those who had not experienced OA found it difficult to understand the pain and disability caused by OA. Therefore, they believed other people often dismissed their symptoms:

*Mrs N: how they look at us.. some of them I don't think when you say it, they more or less dismiss it because they don't really realise what it entails you see, I mean it's just a word to them like rheumatism and things like that, as I say they have actually got to experience it to know what it's like.. some people say arthritis and it's just like one of those things like you have got a cold or something .. nobody realises.* ***(84, widowed female, retired, no previous knee operations)***

*Mr P: well it's something that is not seen so people don't, they just can't understand the pain you are in.. you know without my trousers on you can see the physical shape of that leg is different to that one so but like I say with trousers on you can't see it and they can't understand why you have got a job to stand up sometimes or do things, or when they say 'come out for.. do this and do that' and you say 'well no this time' you know and like I say it's all according to how you feel at the time, I think it's a case that people can't see the disability so they can't really comprehend it.* ***(48, single male, on disability allowance, no previous TKR)***

Another factor influencing the problem of recognition may be due to the efforts made by the informants to appear 'normal', and 'cover up' their symptoms. Many (18) tended to downplay their symptoms, stating that there were others much worse off than themselves:

*Mr R: obviously there is a lot of people a lot worse off than myself and erm well I think when I go into these Malls and things like that shopping, I think 'Oh dear' they should have seats like this... well not necessarily for me but elderly people like cos there's a lot worse off than me, you can see them walking and I think to myself 'oh I'm not so bad after all like, but it is a pity there isn't more seats to put around for people.* ***(59, married male, retired, previous knee operations)***

*Mrs E: I don't talk about it much, it's something you get on with, I mean there's no good moaning to other people, there's always someone worse off than yourself and I mean the family have got used to it now and if they see me suddenly jerk, they say 'oh our mums knee' and that sort of thing but life just goes on but oh no we don't talk about it much, no point to it, just get on with it.* ***(64, married female, no previous TKR)***

Such views may be part of a larger attitude of "stoicism". Sixteen informants stated that they did not like to talk about their OA and its related disability. They felt that they had to *'tolerate'* the symptoms and *'put up with the pain'*:

*Mr Q: and they go away and you think 'if they only knew, if they only knew how it feels' but we don't say nothing see, just keep yourself to yourself.. you keep yourself to yourself and keep the pain inside, you don't tell them what's it's like.* ***(51, married male, manual worker, previous TKR)***

*Mrs K: they have admired me down here, you know.. how I laugh and joke when I have been in such severe pain, but underneath they didn't know that although I am laughing and joking, they didn't realise the terrible pain I was in, I could have let it overcome me and been really a miserable old nag because the pain is so terrible but then if you.. you can't live like that, you have got to be realistic and try to enjoy*

*yourself through the pain.* ***(75, married female, retired, previous TKR and THR)***

A small number of informants (2) tried to cover their painful symptoms from their partners as they knew they would be upset:

> *Mrs F: but I try to help myself because it does rub off on my better half a little bit because he gets upset to see me struggle.* ***(65, married female, retired, previous TKR)***

Others (4) concealed their difficulties:

> *Mrs J: well sometimes I've been with him, sometimes I've been on my own and I just sit down and if there's a wall somewhere I'll sit on the wall and imagine you are viewing the scenario or something.* ***(71, married female, retired, previous TKR)***

> *Mr X: I tend to pretend that I'm tying my shoelace if I think someone I know is approaching... I'm just that sort of man, a bit proud really.. I don't like them to see that I'm in difficulty so what is important is for me to appear OK from the outsider's point of view.* ***(78, married male, retired, previous THR)***

'Covering up' the symptoms sometimes back-fired on the informants as they became frustrated with their friends' and families' lack of understanding (7):

> *Mrs N: all I get from my friends is that they think I am marvellous I get around like I do, and I keep like I do but I said yes but you don't see me when I am in the flat on my own, and when my neighbour.. she is always inviting me up there because her husband and her daughters, they can't understand it because I am always joking with them but as I said 'it's no good crying'.. so I think I make an effort when I'm in company.* ***(84, widowed female, retired, no previous knee operations)***

## Stigma

Despite attempts to cover up the symptoms of OA, all the informants talked about the stigma attached to having OA. For example, the image of arthritis as a disease of the elderly was common amongst the informants. However, ten of the informants found it difficult to compare themselves to this image as they did not actually expect OA in *their* life-time or feel they were old enough to have OA. It may be that the informants did not want to admit to themselves that they were old:

*Mrs F: oh my God, it's that awful, me with arthritis, I couldn't get my head round it.. I'm not that old yet.* ***(65, married female, retired, previous TKR)***

*Mr T: I think I am still young, well youngish, well I am young at heart, so having arthritis came as a bit of a surprise.* ***(66, divorced male, retired, previous operations)***

The stigma of looking different was discussed by nine of the informants. They found certain activities difficult to perform and were aware of their body image and other people's reactions to them:

*Mrs B: I tend to walk a bit like a gorilla when I get up which is quite embarrassing if you are out, people look at you a bit peculiar as I tend to walk funny.* ***(62, married female, retired, no previous TKR)***

A major stigmatising factor for people with OA was the use of walking sticks. Thirteen informants disliked using any aids as it portrayed the image of an old person and reminded them of their advancing age:

*Mr P: sometimes I use it... again I feel like an old man so I try not to use it that much.* ***(48, single male, on disability allowance, no previous TKR)***

*Mrs E: I feel like an old woman, I feel like that sign for old aged peoples crossing, the old couple bent over. that's how I feel when I have got it.* ***(64, married female, no previous TKR)***

Others (3) were too proud to use a stick and preferred to manage without one:

*Mrs J: not very kindly, not with a stick, you know well it's pride, it's pride. I would benefit from using a stick but I don't like to.* ***(71, married female, retired, previous TKR)***

A number of the informants (6), despite their disabilities, did not like using their walking sticks as they did not consider themselves as 'disabled' enough to warrant using them:

*Mr Y: I know that they say get yourself a stick, I have got my mother-in laws stick upstairs but I won't use them, I'm not ready for that, I still try and get by in my own sweet way.* ***(80, widowed male, retired, no previous TKR)***

*Mrs H: no I don't like it.. no I don't unless I really got to.. I don't use any in here unless I have to. I ain't ones for things like that but it do help, it takes a lot of weight off.. I don't worry about other people but I*

*just don't feel very comfortable with it, I am not ready for it yet, I don't feel comfortable with it myself … there is always something to catch hold off in the house.* ***(68, married female, retired, no previous TKR)***

Another tried to conceal the fact that she needed to use a walking stick by taking an umbrella for support instead:

*Mrs E: I have got a long umbrella which makes it look better but of course you can't take that out when it is sunny so I go for the walking stick but if it's dull then I have got a nice easy crutch with the umbrella… but who wants to walk with a crutch, nobody do they really in their right mind but it just makes life easier.* ***(64, married female, no previous TKR)***

Mr O felt that other people thought that because he had a physical disability he must have a mental problem as well, and therefore felt he was treated differently:

*Mr O: there was a time when I really relied on my crutches I couldn't do anything without my crutches and that was when I really realised peoples attitudes to people with disabilities.. how different they are and how differently you are treated. When people actually realise that you have a physical disability and you need help, erm.. for what reason I don't know but quite often people see a disability, a physical disability, they actually link it to a mental disability and I don't know why they do that and they shy away from you.* ***(40, married male with family, on disability allowance, previous knee operations)***

Negative descriptions given by three of the informants' spouses did not encourage use of walking sticks or help the informant's self confidence. Statements such as, *'she walks like a penguin'*, or *' he rocks like a sailor coming off the ship'* or *'she waddles like a pregnant duck'*, were used to describe their condition. One informant's husband disliked her using a walking stick and she felt that this was one of the reasons why he persuaded her to go ahead with the operation:

*Mrs B: my husband doesn't like me walking with a stick very much… I think he finds it quite embarrassing which is silly really because he's not the one walking with the stick, it doesn't bother me at all. So I don't take it when I am with him [husband].. I just catch hold of his arm if I feel like I need some support.. I think that was part of the reason he kept on and on for me to go to the GPs.* ***(62, married female, retired, no previous TKR)***

On the contrary, seven informants stated that they did not mind using walking sticks. They stated that they had adapted to them and could not do without them now:

*Mrs C: I couldn't go without my sticks.. it helps me and I have got every confidence in those sticks, I really have.. that's my confidence. I would be lost without them.* ***(63, married female, retired, no previous TKR)***

*Mr V: all right that it, it's a big help that is, wouldn't be without it, sometimes the knee is not so bad and I get up and start to walk about without it and then I am looking for it then.. but I don't mind using it at all.* ***(74, married male, retired, previous TKR)***

Mrs N carried on to say that at her age, she was not very self-conscious and therefore was not bothered by the stigma of using walking sticks:

*Mrs N: perhaps if I was younger I might feel a bit conscious but when I say to myself you are 83 years of age, so why are you worried.* ***(84, widowed female, retired, no previous knee operations)***

Furthermore, another informant cherished his ability to walk even with a walking stick, and would rather walk aided than be in a wheelchair:

*Mr W: because I think to myself I would rather walk than be in a wheel chair, I don't care if people make fun of me, I would rather walk than be like the poor souls in wheelchairs and can't move.. I don't want to end up like that if I can help it.. as long as I can get about.* ***(78, widowed male, retired, no previous knee operations)***

Stigma related to employment was discussed by two informants; one did not like the shame attached to being on benefits:

*Mr O: to be living off benefits now, for me it's a nightmare and plus the stigma that goes with it, you know, it's been a bit difficult for me to manage with because I am used to going out and doing a days work and you know coming home and feeling like I have been productive... I don't want to be reliant on anybody, I am an individual, I don't want to be reliant on the system for an income, I want to be able to take responsibility for myself.* ***(40, married male with family, on disability allowance, previous knee operations)***

The second one tried to hide his OA from others at work so he did not get singled out to do *'the easy jobs'*:

*Mr Q: I say I broke it a few years ago.. oh I don't tell them what's wrong with it, I don't tell them it's aching of nothing, I only tell my wife and the family.. cos it is a job at the end of the day, you don't want them to think that you are not up to it... well if you tell them about your knee they think you are on the skive and they say "oh they have given him all the easy jobs" you know, but I want to do the jobs I am supposed to do, or try to do the jobs that I want to do, but I am*

*gradually finding it harder and harder as I am going along.* ***(51, married male, manual worker, previous TKR)***

## Pain and disability

Pain and disability were the two main symptoms that the all the informants experienced.

### Pain

The majority (20) said they had constant pain (intensified by use): the remaining five stated it was intermittent and only caused by use (3), or when knocked (2). Those with constant pain described it as *'a continual dull toothache'* (19), or an *'annoying niggle'* (1). However, the pain was aggravated when they tried to walk or use the knee. Descriptions varied: an *'agonising'* pain (14), a *'shooting'* pain (3), a *'grinding'* pain (3), to a *'stabbing'* pain (5):

> *Mrs J: it's always there.. constant ache.. but that pain there when it catches you, it comes and it's like red hot pokers in your knees, that's the pain, it's like red hot pokers stabbing into your knee.* ***(71, married female, retired, previous TKR)***

In addition to level of use, other factors were also thought to influence arthritis pain. For example, whether it was a 'good' or 'bad' day (9), what time of day it was (3), how active the informant had been the previous day (3) and how tired the informant was (1). Furthermore, ten informants claimed that their pain was determined by the weather. However, there was no agreement as to what weather changes were a help or hindrance to their arthritis. Some stated that the warm weather made their arthritis better, whereas some said that it made it worse. Similar discord was apparent for cold weather or damp/wet weather:

> *Mr R: yeah there's quite a bit of pain from time to time, especially as I say in the damp weather, that's a lot of pain. In the damp weather it's there all the time and if it gets too bad.. in the winter just gone by, for winters just gone by, yeah it's been.. the pain never goes away for too long especially in the winter* ***(59, married male, retired, previous knee operations)***

Interestingly, the only informant who cited changes in the seasons as influencing their pain was the RA informant:

> *Mrs G: (H: it's more noticeable when the weather is about to change) yeah it does.. between seasons like say October and about*

*March, April when the warmer weather is coming because it is a lot worse in the heat cos I get too hot.* ***(68, married female, retired, RA and SLE, previous TKR knee operations)***

Twelve informants spoke of night pain:

*Mrs N: don't talk to me about bed, I go to bed about 1 or 2 o'clock on the morning and I am up again at 5 o'clock, my bed looks as if I have had a wrestling match cos I did ask Mr 9, and I said to him cos I used to go to their meetings, why is it that I can be sat watching television and forget about it but as soon as you go to bed it's just like tooth ache, and he said there's no answer to it.. I dread going to bed, in fact I didn't go to bed for weeks and weeks until my leg started swelling out, I was rushed into hospital and I was told in hospital I had to go to bed because my legs were swelling up just being in this chair all night but I dread going but I have to go.* ***(84, widowed female, retired, no previous knee operations)***

Eight informants denied having night pain stated that their pain eased while in bed as the weight and pressure had been taken off their knees:

*Mr P: when I am laid out flat on my back usually it's quite relaxing, if I need to rest my leg I find it easier to lay down rather than sit down, you know with my leg out straight.* ***(48, single male, on disability allowance, no previous TKR)***

The informants had different ways of dealing with the pain (the different treatments used by the informants is discussed in the next section). More than half preferred not to talk about their OA pain so they would not bother others. This may also be related to the issue of 'covering' up their symptoms:

*Mrs I: you just shut your mouth about it and don't inflict it on anyone else.* ***(69, divorced female, retired, no previous TKR)***

Eleven stated that they knew they could not do much about it so had learnt to live with the pain:

*Mr U: over the years I have learnt to live with the thing and I treat it as that.* ***(70, married male, retired, previous hip replacements)***

Others found that being in company (2) or by keeping busy (10), took their minds off the pain:

*Mrs B: I find when I'm in the garden I forget.. even if it is painful I forget it about it.. I don't know why.. when you are doing things you just forget about it and I try not to sit about too much which I find*

*worse than if I keep moving.* ***(62, married female, retired, no previous TKR)***

One informant felt that setting goals for herself helped her cope with the pain:

> *Mrs F: you have got to have goals, a target, you must because you need something to look forward to and I think this is how you really cope with it in the end.. you got to still think, I must do stuff.. you have got that goal, I want to go to the toilet, right you have got to go but you must try to do it .. I mean I have been told off in the past for this, being too independent if you like but I think once you give in, that's it.* ***(65, married female, retired, previous TKR)***

## Disability

In addition to the pain, all stated that they had some disability, although this also varied from relatively mild (able to continue with daily life, 17), to severe (housebound, 8). All informants described the activities that were affected by their OA. The informants discussed the activities in daily living (ADLs) and leisure activities they were unable to do as a result of having OA (see Tables 6.1 and 6.2). As can be seen from the tables all informants found walking difficult. The difficulty in walking varied from 20 who could only walk short distances, to three who could hardly walk at all, and another two had to rely on a wheel-chair. Difficulties in walking not only affected day to day chores but also social activities. One informant had to give up his job because of the walking involved:

> *Mr O: I worked for the local authority and housing associations, developing properties and managing properties.. so there was a lot of walking, particularly on building sites, up and down ladders, checking people's work, and a lot of driving. I literally collapsed with the pain at work, I couldn't walk, the leg went and er.. it just wouldn't move, I had to be carried, and er.. I just didn't know what to do so I went to my GP who put me on a course of tablets and told me to stay in and rest and then he kept signing me off 3 months at a time.* ***(40, married male with family, on disability allowance, previous knee operations***

All informants also found stair climbing difficult; some (8) found ascending stairs more strenuous while others (4) found descending stairs more demanding:

> *Mrs E: descending stairs, it's like going downhill as well when you are walking, your joint is going against it, your joints are straight, it's easier to go upstairs than it is to come down, I come down one step at a time.* ***(64, married female, no previous TKR)***

Other activities such as bathing/dressing, sitting, standing were difficult. Eight informants said that they were forced to become reliant on their partners for certain activities, such as washing and dressing. All were very grateful for this help but one informant explicitly stated that she found it difficult to come to terms with her lack of independence:

> *Mrs C: he has to help me put my pants on and I don't like that, it's not nice, and sometimes he has had to help me take my jumper off and all that.. I am an independent woman and it is not nice. (H: no she doesn't, well you see the trouble is we are both country people and we very very independent, country people always are, extremely independent and that does affect her, the fact that she has got to rely on me)* ***(63, married female, retired, no previous TKR)***

All informants also described leisure activities that they could not do as a result of having OA, such as being unable to shop or go on holiday, being restricted in church activities, being unable to go to the theatre or football matches.

## Emotional impact of pain and disability

The emotional effects of pain and disability were numerous. Fatigue was common (9) and a small number of informants (3) were irritable and short-tempered:

> *Mrs K: the pain, it can be intolerable some days, really intolerable and some days I could sit here and I could scream and I could just snap my husbands head off for nothing.* ***(75, married female, retired, previous TKR and THR)***

A major grievance with pain and immobility was that it had *'taken the enjoyment out of [their] life'* and interrupted their normal way of living:

> *Mrs K: but I don't, because it don't do you any good, so it's the pain, plus the fact it has inhibited my way of living and it has took away basically part of my life because we can't do what we want to do in the twilight of your life, we can't do it.. it has stopped us.* ***(75, married female, retired, previous TKR and THR)***

*Table 6.1 Basic activities affected by the informant's OA*

| | Walking (25) | Stair climbing (25) | Bathing/ dressing (18) | Sitting (16) | In/out of car (14) | Standing (13) | Bending (12) | Kneeling (7) | Rising from bed (5) | Lifting (2) |
|---|---|---|---|---|---|---|---|---|---|---|
| Mrs A | ✓ | ✓ | ✓ | | | ✓ | | | | |
| Mrs B | ✓ | ✓ | | | | | | ✓ | | |
| Mrs C | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | |
| Miss D | ✓ | ✓ | | ✓ | | | | ✓ | | |
| Mrs E | ✓ | ✓ | ✓ | | ✓ | | ✓ | | | |
| Mrs F | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| Mrs G | ✓ | ✓ | ✓ | | | | | | | |
| Mrs H | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | |
| Mrs I | ✓ | ✓ | ✓ | ✓ | | | | ✓ | | |
| Mrs J | ✓ | ✓ | | | | | | ✓ | | |
| Mrs K | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | ✓ | |
| Mrs L | ✓ | ✓ | ✓ | ✓ | | | | | | |
| Mrs M | ✓ | ✓ | ✓ | | | | ✓ | | | |
| Mrs N | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | | | |
| Mr O | ✓ | ✓ | | | | | | | | |
| Mr P | ✓ | ✓ | | ✓ | ✓ | | ✓ | ✓ | ✓ | |
| Mr Q | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | | ✓ | ✓ |
| Mr R | ✓ | ✓ | | | ✓ | ✓ | | | | |
| Mr S | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | |
| Mr T | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | | |
| Mr U | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | | ✓ |
| Mr V | ✓ | ✓ | ✓ | ✓ | ✓ | | | | ✓ | |
| Mr W | ✓ | ✓ | ✓ | | ✓ | | ✓ | | | |
| Mr X | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | | | |
| Mr Y | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | |

*Table 6.2 Leisure activities affected by informant's OA.*

| | Shopping (16) | Holiday (15) | Socialising (15) | Sports (11) | Housework (11) | Hobbies (10) | Gardening (9) | DIY (5) | Church (4) |
|---|---|---|---|---|---|---|---|---|---|
| Mrs A | | ✓ | | ✓ | ✓ | | | ✓ | |
| Mrs B | | | | | | | ✓ | ✓ | |
| Mrs C | ✓ | | ✓ | | ✓ | ✓ | ✓ | | |
| Miss D | ✓ | | | ✓ | | | | | |
| Mrs E | ✓ | | ✓ | ✓ | ✓ | | | | |
| Mrs F | ✓ | ✓ | ✓ | | ✓ | | | | |
| Mrs G | ✓ | ✓ | | | ✓ | | | | |
| Mrs H | ✓ | ✓ | ✓ | | | ✓ | ✓ | | |
| Mrs I | ✓ | | | | | ✓ | ✓ | | ✓ |
| Mrs J | ✓ | | | | | ✓ | | | ✓ |
| Mrs K | | ✓ | ✓ | | | ✓ | | | ✓ |
| Mrs L | | ✓ | | | ✓ | ✓ | | | |
| Mrs M | ✓ | ✓ | ✓ | | ✓ | ✓ | | | |
| Mrs N | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | ✓ |
| Mr O | ✓ | | ✓ | ✓ | ✓ | | | | |
| Mr P | | ✓ | ✓ | ✓ | | ✓ | ✓ | | |
| Mr Q | | | | ✓ | | | | | |
| Mr R | ✓ | ✓ | ✓ | ✓ | | | ✓ | ✓ | |
| Mr S | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Mr T | ✓ | ✓ | ✓ | ✓ | ✓ | | | | |
| Mr U | | | ✓ | | | | ✓ | | |
| Mr V | | ✓ | | | | | ✓ | | |
| Mr W | ✓ | | | | | | | | |
| Mr X | | ✓ | ✓ | | | | | | |
| Mr Y | ✓ | ✓ | ✓ | ✓ | | | | ✓ | |

In addition, a loss of independence was implied or cited by nearly all the informants:

> *Mrs N: but no I would like to be able to move around more... not have to rely on somebody coming for me like you know and as I say like with this Dial-a-Ride, it's a good thing, but I would love to think that I could go and get on the bus and come home when I like whereas you are tied with time you see with them.. so it's independence and I mean, well I would like to be able to go further afield shopping, not just go to the silly little shops up here.* ***(84, widowed female, retired, no previous knee operations)***

The majority (20) of informants also discussed the unpredictable course of OA:

> *Mrs F: it just gives away, it just gives and then locks, you can't seem to be able to control it, it just seems to grip.. I think the best way to describe it is you think it is going to break.. that's what's worrying, when it locks.* ***(65, married female, retired, previous TKR)***

Two informants felt that they had also lost control of their lives because of the restriction of their OA:

> *Mrs K: I want to be still up and active and doing the things and being in control of my own life, you know, because when you find you cannot control your own life, it's awful and having to depend on someone, mentally as well, erm.. this to me is terrible because I would like to be doing things for myself to give me something to do.* ***(75, married female, retired, previous TKR and THR)***

As a consequence more than half of the informants felt frightened about doing certain activities, as they felt physically vulnerable:

> *Mr S: some days I can't have a shave because of the simple reason, it's mentally more or less, it's in the mind cos it has never happened yet but I am frightened one of the legs is going to go and I am going to go down and cut myself to pieces like, which is obvious like and you have got to watch steps.* ***(64, married male, retired, previous knee operations)***

> *Mrs F: I get to the third stair and I can go half way and then I stop, I use both legs, I am very good, I mean I try to keep them both working but when I gets to the last step I don't know whether to put my left one up or my right one, which one is going to hold me to go that little way along... but it is just those few at the top.. some days more than others I just get that horrible feeling that you are going to go back.* ***(65, married female, retired, previous TKR)***

The physical and emotional impact experienced with OA had a direct effect upon the informant's ability to socialise and partake in activities, causing isolation (16). This

isolation was a result of an intentional withdrawal, by the informants, from social participation. For example, Mr O, when he first started using his walking sticks, just stayed in because of other people's negative reactions to his walking aids. Other informants (5), as they experienced more and more uncomfortable moments also tended to avoid social interaction:

> *Mrs N: when it I was my 70th birthday, my sister arranged a surprise birthday for me, everybody was there but I know I really spoilt that party for them because I was a miserable, I suppose on about a couple of occasions I accepted an invitation to go out for lunch but I say 'raincheck, raincheck now', I refuse to go because I know I am not fit to be in company* ***(84, widowed female, retired, no previous knee operations)***

Withdrawing from activities meant that the informants could avoid feeling that they had failed to meet other peoples' expectations (1):

> *Mrs M: well I just couldn't see myself going on the coach, I thought I would be a nuisance so of course I cancelled and it wasn't very nice for the person I was going with, I suppose, but.. she never went either, but then she got a bit cross at first but I suppose she got over it but we have made no plans for this year, I don't want to let her down again.* ***(81, widowed female, retired, previous TKR)***

In addition, choosing isolation over social interaction meant that some informants (3) avoided feelings of guilt over holding others back or being a burden:

> *Mrs F: I wouldn't like to think I was holding someone else up by limping and hobbling along, you know, that would upset me more than anything.. so that's what I want, just to get on with my life, get up and go, it's because I feel guilty about it perhaps.* ***(65, married female, retired, previous TKR)***

Feelings of frustration were cited by all of the informants, predominantly resulting from the loss of ability to do 'normal' activities or do activities that they used to do, the increased fatigue and weakness, as well as the effort and time that activities take:

> *Miss D: not being able to use it properly, not being able to get out of chairs and I think that this is one of things which is frustrating, mostly you can't get comfortable in a chair because, you know it's not right, it's too high to.. high enough to help me get out but erm.. it's too high to settle and relax comfortably and it just affects everything…. and it takes a little bit longer to do everything.. I certainly can't do anything in a hurry which is a nuisance.* ***(64, single female, retired, no previous TKR)***

The frustration of not being able to control activities or the pain could result in a feeling of helplessness (10):

> *Mr Q: you know that, if you are going to work, you know that by the afternoon you are going to have a bad one, you know it and it does get you down, you get really cheesed off, you know, you can't do anything about it.* ***(51, married male, manual worker, previous TKR)***

This feeling of helplessness was more evident when the informants indicated they had been very active throughout their lives (4):

> *Mrs K: (H: so basically she is virtually incapacitated as regards to movement) and that makes me so angry because I used to be a home help, so I used to help other people and I have lead a very active life.. to become like this now, it is frustrating.* ***(75, married female, retired, previous TKR and THR)***

Half of the informants stated that they got very depressed as a result of having OA (13), while the other half (12) stated that they did not. The pain and frustration of having OA was the main origin of depression:

> *Mrs C: but it is the frustration that gets you down and that's what makes you depressed, you know, you see things and you can't do them, that is the problem, that is the real problem oh yeah sometimes I can get very depressed, I really can, I have crawled on the floor crying when I have been in a lot of pain.* ***(63, married female, retired, no previous TKR)***

Those informants who said they never felt depressed stated that they had accepted their OA and had a positive attitude about life and the future. They refused to give up even when the pain and disability were present. *'I am not going to be knocked down by any disease,' 'it's just sheer determination', 'you have to stay active and help yourself'*, and *'you have to have a positive attitude'* were among the responses to various questions on how they stopped depression from becoming too overwhelming and consuming. They felt it important to lead as *'normal a life as possible'*:

> *Mrs J: you've got to have a positive attitude to life, that's what you got to have... and you haven't got to grumble, no good to grumble, you mustn't grumble, you just take things as they come and cope with things as the come.... it's probably the whole attitude you take to these things, I mean if you take a positive attitude I suppose things can turn out a lot better.* ***(71, married female, retired, previous TKR)***

Concentrating on what they could do as opposed to what they could not do was also an important factor:

> *Mrs I: you tend to think about the things you can do because a bottle is never half empty, it's always half full.. It's not a death sentence.. but as long as you concentrate on what you can do and don't keep whinging about it.* **(69, *divorced female, retired, no previous TKR)***

In addition, it was imperative for psychological and physical health of many of the informants to continue to pursue activities that brought satisfaction and happiness to them:

> *Mrs C: I have just been over now to have my hair cut and washed because when I am over there I can sit down and have it washed because.. which I think it not only helps keep me up together but it makes me feel better.. um, and I think it is important not to let yourself go if you can help it.* **(63, *married female, retired, no previous TKR)***

Gaining knowledge and becoming educated about OA and its disease course helped some informants to help control the fear of the unknown. Five informants felt it was the *'not knowing'* that was *'the hardest part to accept'*:

> *Mrs K: I want to know what is happening to my body, it's my body and I want to know what they are doing to my body, after all said and done, and if you don't ask, you don't know and if you know what's taking place in your body, then you can learn to cope with it.* **(75, *married female, retired, previous TKR and THR)***

> *Mrs F: it's not knowing that is the hardest part to accept and when you don't get a straight answer from someone who ought to know.. you know he did it.. cos I am a person who loves to know everything, I just like to know, I have got a curious mind and I think it would help.* **(65, *married female, retired, previous TKR)***

In general, the informants felt that there was a lack of information given to them about OA. The idea of patient groups was suggested by five informants, to enable the informants to share views and experiences and know that they are not the only ones suffering:

> *Mr S: I have never had no communications, never been to a club or anything like that where you can meet or have a chat socially and the best thing is to talk like I am talking to you or my wife or my doctor, I comes out lovely but nothing has ever been done for people like that.. talking about their illness, like all these other illnesses they do now, they*

*talk amongst themselves.* ***(64, married male, retired, previous knee operations)***

## Family life impact

Of the 25 informants in this study, 16 were married (two informants still had young children at home) and the remaining nine were either single, divorced or widowed. All the informants discussed how their OA impacted on their family. Although this impact was often detrimental to family life, 12 of the 16 informants indicated that it was important to have the support and understanding of their spouses:

> *Mrs F: with the help from your family, it helps a hell of a lot if you have got someone who can give you a bit of get up and go when you feel down and that.* ***(65, married female, retired, previous TKR)***

> *Mr R: fortunately my wife, shall I say understands the situation and if I say for instance the knee is terrible, she says 'that's all right, just get your papers and get your leg up'.* ***(59, married male, retired, previous knee operations)***

> *Mrs K: he cares for me so he knows what I am going through.. he can only see by the look on my face what I am into, you know, I am fortunate that I have got such a husband who cares and he knows me.. actually he knows me before I can say.. he can see what is actually happening before I can tell him.* ***(75, married female, retired, previous TKR and THR).***

As a result of having OA, responsibilities around the household had to be transferred to other family members who could better handle them (4). This caused feelings of guilt:

> *Mrs F: my husband does all the washing up and he says he can cope but I say let me wipe, you want to help and you want to do things but your body doesn't really feel 100 per cent to do it, I mean I say to my husband, 'leave it today', it's because I feel guilty about it perhaps.* ***(65, married female, retired, previous TKR)***

Difficulties in looking after and playing with grandchildren were also apparent for five of the informants:

> *Mrs E: well it's like we have got a great-grandson and er.. he is six months old and I can't lift him because I dare not lift him because if my leg goes then I could drop him.* ***(64, married female, no previous TKR)***

Living with OA also had a major impact on the marriage of a number of informants. One informant was aware that his wife had to be careful not to touch his knee while in bed. This had consequences for their sex life:

> *Mr O: Quite often, there used to be areas of the knee that were extremely sensitive to touch so basically I would have to make sure that if I laid on my side that my legs would have to be in such a way so that they weren't resting on each other, my wife would have to be very careful to not bang into me, so sex is very difficult.. so it is awful for her as well, it was not just me living with it.* ***(40, married male with family, on disability allowance, previous knee operations)***

Three other informants lost their temper and patience with their partners:

> *Mrs F: I mean it might sound cruel at times but I say 'shut up you don't know what I am going through', but I try not to say it because it is not fair to pull someone down who is trying to make you feel better.. so perhaps sometimes things get a bit frayed at the edges if you like with us because you think 'what is it all about'.* ***(65, married female, retired, previous TKR)***

Another two of the informants found their husbands were too *'over-protective'* at times:

> *Mrs E: my husband, you know ...I think he wraps me up in cotton wool... it's 'ooh don't do this, don't do that' you know, 'watch that knee' and he could be sat in the recliner and I am here and if I move it's 'watch that knee', for goodness sake, leave me alone, he fusses, it's only that he worries but you know, I think let me do what I feel I can do but he is watching every movement, you mustn't do this or that, and I think 'well if I feel I can, I am capable of doing that much more then I am going to do it, you have got to listen to our own body.* ***(64, married female, no previous TKR)***

The impact of OA on the informants upset their partners as they did not like to see them in so much pain and felt helpless as to what to do (4):

> *Mrs F: but I try to help myself because it does rub off on my better half a little bit because he gets upset to see me struggle.* ***(65, married female, retired, previous TKR)***

> *Mr V: [Mrs V's wife] I mean I sit here sometimes and he goes 'oh' and there is absolutely nothing I can do, you know it is awful when you see someone in pain but I can't do anything.* ***(74, married male, retired, previous TKR)***

One informant said he was too proud to ask for any help from his family:

> *Mr Y: I am very independent, my family know it, I have got a son across the road and they call me all the names under the sun because I*

*am too proud to ask them to do anything, I mean I have always been that way inclined.* ***(80, widowed male, retired, no previous TKR)***

Other family impacts included the affects on their children's lives. One informant had to depend on his children to do the shopping. He was aware that this affected their social life as well as his role as a father:

*Mr O: there have been times when I have been trying to get up out of the chair and the youngest girl, she's only just turned 8, and she's a skinny little thing and she's there 'Daddy do you want a hand ' and try to pull me up and it's just daft. I just want to be able to do everything myself and get on with it so that my kids are free to enjoy themselves with what they want to do ... but it's like my kids looking after me instead of me looking after them.* ***(40, married male with family, on disability allowance, previous knee operations)***

Three of the five informants who were widowed and lived alone admitted that it would be nice to have the company of their partner:

*Mrs M: but I got no family, just my sister.. only myself to look after and worry about now... sometimes I mean it would be nice to have a shoulder to lean on or an arm to lean on but I know that's not possible, I got no husband and I got no one coming here, no partner.* ***(81, widowed female, retired, previous TKR)***

However, another said she was glad she had no family so she did not make anyone else's life a misery:

*Mrs N: that's why in a sense I am glad I'm on my own, so I've got no one to make life a misery for by taking it out on them.* ***(84, widowed female, retired, no previous knee operations)***

## Embodiment

Many of the informants used depersonalised language when they referred to their knee (i.e. *'it', 'this', 'the joint'*) and some even gave their knee a gender, (always masculine), irrespective of their own sex:

*Mrs F: when he's all right I thinks I will put up with it but then when he gets bad I think oh I have to get something done with it.* ***(65, married female, retired, previous TKR)***

*Mr P: well the last time I went up, the chap I seen he went off to get Mr 1 and I was waiting for quite a while, you know this was after he said 'well it looks like we will be replacing the joint'.* ***(48, single male, on disability allowance, no previous TKR)***

The informants also compared their knee to a mechanical engine:

> *Mrs J: it's like an engine really you know your engines conks out and you got to get it going.* ***(71, married female, retired, previous TKR)***

> *Mrs I: it's a combination of silly things with me that if one part of the engine is gone, the whole car won't start.* ***(69, divorced female, retired, no previous TKR)***

The informants were asked how they felt about having part of their body being replaced. Out of the 22 informants who commented, the majority were unconcerned about this and had not even thought about it. However, there were five informants who, for different reasons, were upset by this issue. For example four informants did not like the idea of having a replacement, due to fear of rejection (*'I don't fancy it, I thinks I could reject it'*), the fear of the new prosthesis rubbing (*'that's what's worrying me, will it rub, will I be in a lot more pain after'*) and actual process of cutting the body part away (*'as I say whether it's the thought of like the hack saw, I think it's just the thought of part of your body being cut away like'*). The most vehement argument came for a religious man, who, as a Christian, did not agree with part of his body being replaced with something man-made:

> *Mr S: not really happy because I am a Christian.. it's not just the thought it's why.. why couldn't they come up with something else, it's been around long enough arthritis.. but man shouldn't mess about with anything, like the food or the body, with this cloning business, that's absolutely disgusting… and also there is no guarantee that the body might not accept it and at the same time it could turn poisonous, that's a definite factor, plastic.. and personally now I have had so much trouble with this.* ***(64, married male, retired, previous knee operations)***

## Managing regimens

The different treatments used by the informants are shown in Table 6.3. As can be seen, all the informants were on prescribed analgesics for their OA, and a smaller number of informants had tried alternative medicines. This section describes the informants' attitudes towards taking medications.

*Table 6.3 Different treatments used by the informants*

| Treatment | No. of informants |
|---|---|
| Simple analgesics only | 6 |
| NSAIDs only | 8 |
| Both NSAIDS and analgesics | 11 |
| Creams/Sprays | 7 |
| Homeopathic remedies | 4 |
| Meditation (mind over matter) | 3 |
| Cod liver oil tablets | 3 |
| Magnetic bracelets | 2 |
| Osteopath | 1 |
| Acupuncture | 1 |

**Prescribed medication**

Although in general the analgesics did help to ease the pain, 17 of the informants had negative views about them, sometimes resulting in a reluctance to take the medication at the prescribed amount. The negative views were dependent on a number of reasons; the informants often cited more than one apprehension. Major causes for concern were side-effects (10) and addiction (9) associated with taking medication. Side-effects ranged from indigestion, stomach ulcers, weight gain, constipation, rashes to dizzy spells:

> *Mrs C: I have been on so many tablets, one lot of tablets brought me out in a hell of a rash, the other lot of tablets just sent me like a zombie, I didn't know what I was doing, that had to be stopped and one lot of tablets made me feel very giddy and sick and my doctor stopped that and then another lot of tablets I couldn't breathe, one lot of tablets sent my .. not my hands but my feet swelled up terrible and she stopped them straight away. I just couldn't take it, I was so light headed. I mean there are anti-inflammation tablets that I have tried but I get a lot of indigestion and heart burn, they call it heart burn, I feel very sick and giddy and my head is whizzing.. when it is so very very bad even two paracetemols make me feel queer.* ***(63, married female, retired, no previous TKR)***

Nine of the informants, in an attempt to regain some control over their illness, altered the doses of the drugs. The most common form of non-compliance was to take fewer tablets than the prescribed dose (5):

> *Mrs A: I take them but the doctor said I could take 8 tablets a day but I won't take 8 tablets a day. I only take about 2.. the body gets used to it.. I know they got to give them you in hospital, I don't mind that but when you are at home, I don't like taking them.* **(55, *married female, retired, previous TKR and THR, club foot*)**

Two informants who also took medication for co-morbidities were keen to limit the number of pills they took per day:

> *Mrs K: I don't want to be pill popping all the time because I have been on so many tablets that I am fed up with them.* **(75, *married female, retired, previous TKR and THR*)**

Others reduced the doses by taking their tablets fewer times a day. One informant *'struggled hard not to take them during the day'* so she would feel better about taking them at night. Three informants only took the pain-killers when in desperate need:

> *Mrs B: I don't take pain killers very often now which is something, I mean I suppose I could but that is something I won't do not unless I'm desperate, and I got to be really desperate, really in a lot of pain to take anything at all.* **(62, *married female, retired, no previous TKR*)**

Mr T refrained from taking pain-killers as they wanted to feel the pain in order to rest the leg and not wear the joints out unnecessarily:

> *Mr T: yeah and I don't take pain killers, well I haven't taken them for years and years and years because I wanted to feel the pain and rest my leg I didn't want to wear joints.. I wanted to know what was going on, I wanted to feel the pain so I knew when I had to get my legs up.* **(66, *divorced male, retired, previous operations*)**

Such reductions left the informants experiencing considerable levels of pain and discomfort:

> *Mrs B: I did take anti-inflammatory tablets a couple of years ago but I found they caused problems with my stomach and I thought well I'd rather put up with the pain and an upset stomach as well because it's not very pleasant.* **(62, *married female, retired, no previous TKR*)**

A less common theme in non-compliance involved the informants taking *more* tablets than prescribed. A couple of informants took more than the prescribed dosage as they had not yet experienced any of the side-effects mentioned on the leaflets:

> *Mrs N: I think to myself even if I can't sleep if I could just have the relief, you see so whether it's right or wrong I don't know but I do take 2 at once but of course my sister says you are wrong, you should only take one but I says it hasn't done me any harm up until now and for the rest of the day I will take paracetemols.* ***(84, widowed female, retired, no previous knee operations)***

## Complementary medication

Additional medications, such as those purchased over-the-counter, or complementary medicines, were used in response to inadequate symptom control of the prescribed analgesics or adverse effects from the other drugs. They were used sometimes instead of, or sometimes as well as, prescribed medications. More than half of the informants had tried complementary medicine, such as homeopathy and meditation (see Table 6.3). They were, in general, perceived as harmless although they were unsure about how they worked:

> *Mrs I: it's a magnet, it's harmless, and I really think it has eased it, it's something to do with the iron in the blood, I don't know, but it's the oldest cure and it seems to work.. well all old cures do.* ***(69, divorced female, retired, no previous TKR)***

In general, with regard to the homeopathic remedies, two informants felt they were too old to start taking them, as they thought the real benefits of the tablets only came after long-term use:

> *Mr V: we have gone on to cod liver oil capsules, I think it is like shutting the stable door after the horse has gone really but there we are doing something aren't we.., well I mean you have got to think that it does cos otherwise it won't, will it I suppose it does help a little bit maybe as it is supposed to oil the joints and it is supposed to help with your heart.* ***(74, married male, retired, previous TKR)***

Three informants preferred to deal with the pain with *'mind over matter'* techniques. One informant believed that using this technique was why he coped so well with the pain. The other informant said he has to *'walk through the pain barrier'* to overcome his pain:

> *Mr S: it's the body and mind, I will tell you that now, well to cure the pain I told my doctor an old Chinese philosophy, it's mind over matter, a lot of people scoff but some doctors believe it that it is possible*

*to control but the mind over matter I have done it, because your mind is here [points to head] and the matter is your leg and you can control it to a certain extent.. I got pain killers, I have taken them for the last 11 years.. so you say it's not there, 'I can't feel this, this is not here, my leg is all right, I am going to do what I want to do', you keep saying that to yourself and it works.. that's why I got on so well, I mean to look at me I am quite a fit man, I am 64 now and I don't look it and I don't feel it.* ***(64, married male, retired, previous knee operations)***

## Summary

Despite the general acceptance that OA was age-related, the informants attempted to explain the onset of their OA in the context of events in their lives. The pain and disability experienced was chronic and debilitating, and caused many emotional symptoms. However, despite this major impact, they did not view their joint problems to be an illness. Instead OA was viewed as a physical disability, an inconvenience, or something to put up with as a part of old age. Due to the negative image associated with OA (elderly, crippled, dependency) many were distressed at the prospect of being perceived as old or disabled. They went to lengths to mask their symptoms from others to maintain a positive self-image. As a result of having a 'normal' condition and their attempts to cover the pain and disability most of the informants spoke of the lack of understanding on the part of others to the effect of their symptoms being dismissed or deemed insignificant.

All the informants worked out ways to cope with their arthritis. The main coping strategy was to 'fight' the arthritis. Self-control, stoicism and a refusal to be *'beaten'* by their OA were cited often and they stated it was important to remain active and pursue and concentrate on activities that they could still accomplish. Other informants stated that they were very depressed by their situation. These informants tended to be those who were more resigned to the fact that nothing could help them relieve the pain. Although the medications eased the pain of the OA many informants had concerns about the side-effects, and image of addiction and 'lack of control' associated with tablet taking. As a consequence, some adjusted the dose of their drugs in certain ways (usually by limiting the number of tablets taken) in an attempt to regain control over their life. Alternative therapies were also used as a substitute or supplement for their GP prescriptions.

## Pathway to surgery

This section recounts the informants' view of their referral and listing for surgery. The majority (19) were referred to the hospital by a GP, two were referred by a physiotherapist and the remaining four were put on the list by a consultant at a follow-up appointment for their other replaced knee or hip. The description of this process by the informants gives an insight not only into the triggers of their decision to seek help, but also hints at some of the factors related to GPs' decisions to refer and consultants' decisions to list for surgery.

### Decision to seek help

This section presents the reasons why the informants delayed seeking help, as well as the triggers for choosing to seek medical help for their knee OA.

#### Reasons for delaying seeking help

There were three major reasons given by the informants to explain why they had delayed seeking help for their knee. For example, eight informants felt they were able to tolerate or endure the OA pain and disability they experienced:

> *Mr Y: no I don't go up and talk about my legs, I usually grin and bear it, that's the way I am, do a little bit of work and hope that would ease it or work it off.* ***(80, widowed male, retired, no previous TKR)***

Another reason for delaying medical help reflected the embarrassment of going to see the GP. One informant felt embarrassed because his medical notes were so thick he had to spend a long time in the consultation room with the GP, when there was a waiting room full of people outside. In addition, as a result of living in a small village, the informant tended to know many of the people in the waiting room, and was therefore self-conscious not only about the amount of time he spent in there but actually the fact that he was there in the first place. Another informant delayed going to see the GP as she found the examination intrusive and embarrassing:

> *Mrs C: I don't go if I can help it.. I have got nothing against them but I just don't like them, I don't like doctors, I don't even like it when the doctor examines my knee, I don't like that one bit.. it's the loss of dignity probably and the times I have been told to relax, I find that difficult because I don't know them.* ***(63, married female, retired, no previous TKR)***

Several other informants refrained from going to the doctors often because they believed that there were others worse off than themselves, reflecting a stoical attitude:

> *Mr Y: I keep out of the doctors, there are worse off than me so I keep out.. the only time is to get my prescriptions in… I got nothing really to go up there for and there's always a surgery full of people in a far worse state than you, so no I don't bother them at all… that's life for me.* ***(80, widowed male, retired, no previous TKR)***

## TKR compared to THR

An interesting theme that emerged from the interviews (although not explicitly given as a reason for delaying medical help) was the perception of the effectiveness of TKR in comparison to THR. One-third believed that TKR was an inferior operation compared to THR. This may be due to early mixed results in the 1970s (see chapter one):

> *Mrs G: I mean before I had this I didn't know they did knee replacement I knew they did hips but they did hips a lot sooner than they did knees.* ***(68, married female, retired, RA and SLE, previous TKR)***

> *Mr U: yeah I haven't had good reports of knees whereas with hips have been generally very good.* ***(70, married male, retired, previous hip replacements)***

They had heard from others that the TKR operation was more difficult to perform than the THR operation, and thus was more likely to result in worse outcomes. The knee was also thought to be more problematic because it bears more body weight than the hip:

> *Mr U: cos the knee operation is a bit more problematic than the hip isn't it, so people say.. from people that I know who have had it done, you get the impression that things can get more complicated I suppose.* ***(70, married male, retired, previous hip replacements)***

> *Mrs L: and of course I do believe the knee operation.. years ago I wouldn't have it, no way, because they said the hip was good but the knees weren't too good.. they have improved over the years I believe but years ago they weren't so sure of the knees so I used to say I'd never have my knees done of course when you get to such pain.. and my husband said 'oh no don't have it done, you know where you are' but now I feel a lot different now.* ***(80, widowed female, retired, previous THR)***

The negative opinions towards TKR appear to be slowly changing. The majority of the informants believed that there had been great improvements in TKR in the past decades. This change in attitude came from media coverage and information leaflets:

> *Mr X: I think they are getting better results now than they were 10 years ago, well that's what I think and I think you are more willing to go and have a knee replacement since my hip done and that was successful.. and they are improving aren't they or they have improved over the last 10 years I'm sure.* ***(78, married male, retired, previous THR)***

> *Mrs M: but they have improved on it now haven't they?.. made it lighter now.. or has that been put into practice now what I saw on the television about lighter joints (I: I didn't see that) well I saw it on the telly but I mean whether it's being done as general I don't know do I.. because sometimes the leg sort of does feel heavy.. but I mean that might be in the mind mightn't it.. but it feels like that way.. heavy.* ***(81, widowed female, retired, previous TKR)***

## Reasons for seeking help

The triggers for seeking help included the perceived increasing severity of pain and disability (14):

> *Mrs B: I went to see the doctor to tell her about it cos I mean I couldn't walk very well at all, I couldn't take the dog out or anything.* ***(62, married female, retired, no previous TKR)***

> *Mr S: I finally went because I had all that pain and it was getting worse.* ***(64, married male, retired, previous knee operations)***

> *Mr Y: erm.. well this pain in my legs, I couldn't bend them, both legs, I had to go to the GP.* ***(80, widowed male, retired, no previous TKR)***

Nine informants were also forced to go and see their GP because their knee had either collapsed or had been injured:

> *Mr W: it went all of a sudden on the crossing.. matter of fact they took me to a friend and I missed a step and down I went so then I had to go to my GP.* ***(78, widowed male, retired, no previous knee operations)***

> *Mr V: [informant's wife] then he got stuck getting out of the car one day and couldn't move.. fortunately there was a builder there and he had to pull him out of the car, embarrassing for him of course.. and that was when that something had definitely to be done, just couldn't*

*carry on, [Informant: so that is when I went to the GP and he referred me].* ***(74, married male, retired, previous TKR)***

*Mrs I: it did really give way very badly one day.. in fact I was in church that day and I had been doing some cleaning, I used to do church cleaning and the vicar was stood behind me and he spoke to me and I turned round quickly and I went round but my knee stayed put and I fell over and he caught me, they took me to my GP.* ***(69, divorced female, retired, no previous TKR)***

A smaller number of informants (4) were coerced into seeing their GP by their spouses:

*Mrs J: my husband kept saying to me 'you should go and have the other one done, you should go and see about it', so I did in the end.* ***(71, married female, retired, previous TKR)***

*Mrs B: I was really getting frustrated cos my family had been on for me to go and see the doctor and get something done about it I mean I wouldn't have even of gone to the doctors and seen about it when I did if it hadn't of been for my husband and children, they just kept on and on and on and in then end I just went to shut them up.* ***(62, married female, retired, no previous TKR)***

## Referral

The GP acted as the 'gatekeeper' to the hospital for the majority of the informants. Three informants were immediately referred to hospital and found their GPs helpful and willing to refer:

*Mr O: once he realised that there was a problem that he couldn't deal with, he got me into the system as soon as he could to see a consultant.* ***(40, married male with family, on disability allowance, previous knee operations***

*Mr S: my doctor is a friend of ours, he is a family doctor and he is a good friend, he has looked after both of us in illness, especially me and he is marvellous and we are very lucky there, that's one consolation, we haven't got a doctor who writes out a load of tablets or goes like that and says you are all right.* ***(64, married male, retired, previous knee operations)***

However, nine other informants stated that they felt their GP was reluctant to refer them to the hospital. Three informants had to insist on a referral:

*Mrs M: I did ask him but then of course I had to keep on.. it wasn't easy mind.. I don't know why.. I don't know so I kept on.. I went to the doctors a few times before anything happened.. I had to keep on for them to take note.* ***(81, widowed female, retired, previous TKR)***

*Mrs F: I was actually in lots and lots of pain when I used to go to him and my husband said to him 'is this going to be her life', you know, going to the doctors and coming back again and you know yeah.. no quality of life in it at all.. but when my husband asked him if this was going to be it for the rest of our lives then it seemed that things moved in a different way.. we used to say to him 'get me to someone who can do something with it' because it was dreadful.* **(65, *married female, retired, previous* TKR)**

There were several reasons for this perceived delay in referral. For example, a couple of informants felt that their GPs were concerned about the effectiveness of the TKR procedure and the risk of revision operations:

*Mrs L: well I went to a doctor many years ago and he was saying then, 'oh no, he wouldn't advise a knee operation because he said it's not a success', that's how they thought about it, that's a long long time ago, many years ago and over the years they have improved.. I heard a lot people say they wouldn't have a knee done but now it seems they are all having it done.* **(80, *widowed female, retired, previous THR)***

*Mr R: so yes it will have to be replaced but the longer you can hang on, the better it would be so obviously what he said I would accept this.. you know he knows best so whatever he says I'm going to listen to and you know abide by.* **(59, *married male, retired, previous knee operations)***

Others (3) believed that their GP were reluctant to refer as they did not view their symptoms as severe:

*Mr T: I went down to see my GP and he said 'well I don't think you are.. you have to come in here with two sticks he said to get on the list' and I said 'well I ain't coming down to bullshit you but I can hardly walk', even though I walk in like this, when I am telling you I am in severe pain, that's the way I am, I don't want to act, I can walk in on two sticks, I spent years on two sticks through my ops but I do not want to go down to the doctors with two stick to shut him up, I am telling him I am in pain, I am not bullshitting him, I think a lot of people go down there and lie, no I don't lie, I said I have got severe pain in my legs and I want to see Mr 1.. Mr 1 said to me 25 years ago, any problems I get with my legs and when he checked he found out that was true.. so I saw Mr 1, he [GP] said you might not actually see him but I said I don't want an appointment until I actually see the bloke who operated on my legs 25 years ago and within ten days I was in to see him, it was that quick.* **(66, *divorced male, retired, previous operations)***

The view that their GP preferred to try alternative remedies or to prescribe pain-killers, as opposed to surgery, was also raised as a possible reason for a delayed referral:

*Mrs F: but he never seemed to move, it was either rub this in or take that.. he looked at the medicine side of it more, my doctor thinks it [homeopathy] is the end of everything sort of thing, some works and some doesn't, so you don't know really do you, my doctor is in favour of a lot of it so occasionally you get a bit thrown in some where along.. that's why he didn't ever refer me.* **(65, *married female, retired, previous TKR)***

As a consequence of this delayed referral, a small number of informants appeared distrustful of their GP: some felt that their GP hid information from them while others doubted their actual referral:

*Mrs F: although you ask your GP or whoever about what's happening or what is going to happen to you I don't think they do tell you all or perhaps they do not fill you in as much as you want to be filled in… but I just feel they know something and they don't tell you all.* **(65, *married female, retired, previous TKR)***

*Mrs M: I saw him and he said 'oh yes, I will write to Mr 1' well I couldn't say that he never wrote but when anyone writes to Mr 1 it always gets acknowledged and it wasn't acknowledged so I had my doubts whether the message went through.* **(81, *widowed female, retired, previous TKR)***

Furthermore, Mrs E did not believe she had been referred because her GP was a 'young man' and therefore was not interested in her 'old age' problems:

*Mrs E: apparently he did because I even went and saw another doctor in the practice because my doctor is a young one, course moving like we have, I mean my husband was with his doctor for 60 odd years but when we moved we moved out of the area and so being sort of late on the books we have got this young doctor and I thought coming from an old practice like we did, we could talk to the old doctors and they would understand how you were feeling and I thought perhaps being young he wasn't interested in us being pensioners so I asked to see another doctor in the surgery and I said I don't wish to cause trouble but I do feel that an older doctor might understand me better and he said 'oh no he has referred you to Mr 1, he has done all the right things', so I went back to him and I explained my reasons, like having dealt with older doctors I felt.. and he said 'oh no, I wrote to Mr 1 and said how severe you have been in pain ' and he said I should of heard, well as I said he got his secretary to ring and that was the problem, it was going to the old address.* **(64, *married female, no previous TKR)***

Two main reasons were given to explain the GP's decision to finally refer them to the hospital. Seven informants believed that x-ray evidence determined the reason for

referral, although some commented on the fact that their GP appeared to lack confidence in the assessing the x-ray:

> *Mrs H: in the end she sent me for x-rays to see and of course when I went back she said you have got very bad osteoarthritis.. yeah, so she said you can't go on like this cos I really can't walk at all hardly when it's bad, it's really laboured, she said you can't go on like this we have to get something done.* ***(68, married female, retired, no previous TKR)***

> *Mr Y: erm.. well this pain in my legs, I couldn't bend them, both legs and the doctor said 'well go and have an x-ray' so he said 'go down to the hospital 10 as there is no waiting list down there', they did both knees and then he said there was a marked deterioration in the knee since the first x-ray was taken.* ***(80, widowed male, retired, no previous TKR)***

> *Miss D: so I had an x-ray and he said it was ok, the x-ray was ok but he thought that he would rather I had it checked just to be on the safe side so then I saw Mr 2's registrar and then saw Mr 2 three months later and so he just said er.. walked in with the x-ray and said well there's nothing we can do about this, this is in a bad way and explained what the replacement knee was.* ***(64, single female, retired, no previous TKR)***

The perceived severity of the knee OA also influenced the GPs' decision to refer (5):

> *Mrs H: she said you can't go on like this cos I really can't walk at all hardly when it's bad, it's really laboured, she said you can't go on like this we have to get something done.* ***(68, married female, retired, no previous TKR)***

## Indications for TKR

The consultants' decision to list for surgery was described by the informants. Seventeen informants believed their surgery had been delayed. The description of this process gives an insight into the potential indications used by consultants when deciding on whom to operate. The informants' views have been divided into two major themes: what factors they thought should be prioritised, and what they thought happened in practice.

### What should happen

About half the participants accepted that there has to be a waiting list system as resources are limited and there is a high level of demand. These participants suggested a number of different factors they thought should be taken into account when deciding

who should be operated on and when. A major factor was pain, specified by nearly half of the participants, with 'crippling' or severe pain identified as particularly significant by five:

> *Mrs I: 'Well, there is a lot of pain … someone else who is weeping with the pain every morning, obviously this takes precedence'.* ***(69, divorced female, retired, no previous TKR)***

> *Mrs K: 'I am in lots of pain, and I want to be done and have a better quality of life, but if there is someone out there that has been in such agonising pain, although they may not have been in it for as long as I have, then my sympathies would go to them'.* ***(75, married female, retired, previous TKR and THR)***

Mrs K exhibits considerable altruism (above). This was also apparent in five other interviewees who thought that people worse off than themselves should have greater priority:

> *Miss D: 'There's so many people wanting it and I've had to accept there are probably people worse off than I was, and maybe they need it first. And if there are people worse off who need it, then you can't really argue about that'.* ***(64, single female, retired, no previous TKR)***

The idea that people with limited mobility should be given priority was indicated by five participants, with two specifically mentioning better quality of life:

> *Mrs E: 'well I don't know because I have got a certain mobility and I should imagine there are some that are completely incapacitated'.* ***(64, married female, no previous TKR)***

A smaller number of participants cited other factors that they thought should be taken into account, for example, that priority should be given to younger people (4), those in paid employment (6), those paying National Insurance (4), those caring for others (2), and those needing bilateral replacements (1). Although there was evidence of altruism, several participants indicated that it was difficult for them not to show self-interest when thinking about who should be prioritised:

> *Mrs I: 'As it is my knee, I want it done quick … I don't particularly want to wait another 6 to 8 months .. it's difficult to go through your self-interest and your awareness that there are other people who may need it more'.* ***(69, divorced female, retired, no previous TKR)***

Just over one third thought that the surgeon should decide on the basis of medical evidence (such as x-ray changes):

> *Mr X: 'It depends on the specialist.. he has got to decide and sort it out'.* ***(78, married male, retired, previous THR)***

In fact, twelve informants felt that the consultants listed them for surgery on the basis of x-ray evidence of OA:

> *Mr Y: it was a lady consultant and when she looked at the x-rays she said 'there is a marked deterioration in the knee' and she said that the best thing would be a replacement.* ***(80, widowed male, retired, no previous TKR)***

> *Mrs J: he sent me back down for another x-ray and he said oh golly I don't know how you coped with that, so anyway he said he'd put me down on the waiting list and the next thing I had a letter saying I was on the waiting list and that's the last thing 'til you.* ***(71, married female, retired, previous TKR)***

## What they perceived happens in practice

The participants drew on their own experiences to identify several other factors that they believed play a role in who gets a TKR, particularly weight and age. Six said that they had been told that their excess weight was a problem; many of them felt that this was unfair and that the doctors did not appreciate that arthritis led to reduced mobility and therefore to weight gain:

> *Mr P: All I was told was to lose a bit of weight and come back again which, like I said, just annoys me a little bit, well a lot really, because I have had all the problems before I put the weight on … since then I've given up the sport and I've been doing less and less physical exercise I have put the weight on … They tend to look at you as thought it is your own fault … the problems I have got have not been caused by being overweight… I'm overweight because of the problems that I've got'.* ***(48, single male, on disability allowance, no previous TKR)***

However, one informant believed that when a patient paid for a TKR privately, weight would not be an issue:

> *Mrs K: she was a big lady, she was taller than me but big built, she said 'I didn't have it done there.. I have got a wonderful surgeon' and she said Mr 6's name so I said 'oh.. he operated on you.. did he say anything about your weight' and she said 'no' and I thought although she is tall, she was as heavy as me .. but then she said that she belonged to BUPA.. so he [consultant] closed the book and said 'I'll do it next week'.. I was cross with him because she was a big lady and yet no*

*weight was involved and there was me still in agony, almost in tears every time I made a movement but he never mentioned weight to her.* ***(75, married female, retired, previous TKR and THR)***

Ten also thought that age was used as a criterion. Nine reported having been told that they were too young, and again, many felt that this was inappropriate and that they should have been offered their surgery earlier:

*Mrs K I said, 'well can I have something done about it, can I have an operation?' And they said, 'No, you are too young' … I think there should be some way, irrespective of age. I would rather go in and have a check up every 10 years than endure the pain … so if this could be done earlier, you are not like this … I should be out now enjoying myself because I have worked hard all my life'.* ***(75, married female, retired, previous TKR and THR)***

*Mr P: although I think my joint has possibly been bad enough to have a knee replacement for a few years now, the two problems that were put to me were I needed to lose weight and I was too young to have knee replacement, I'm 47, so you know a couple of years ago, 45, and so I don't think they like replacing joints until you get a bit older so erm, ..cos like I say as far as the specialist go because of my age it was always sort of 'well no'.* ***(48, single male, on disability allowance, no previous TKR)***

Four did not know why there was an age cut-off point, whereas the other five were told that it was due to the life-span of the prosthesis. Some (8) were angry that they had to suffer so much pain and immobility, affecting their work and quality of life:

*Mr R: they didn't want to operate too early anyhow you know simply because they say that the knee doesn't last too long so there is no way they or very rarely that they could operate or put in a replacement for a 30 year old, they like to wait 'til they were 50 if possible but that's the way or that's the things I've heard or tried to get out of these consultants, doctors whatever so… whether they are waiting for a little bit longer to hang on which seemed to be the case.* ***(59, married male, retired, previous knee operations)***

*Mrs K: I mean having joint replacements earlier.. having it done and this is what I said, if I could have had that done when I was 42, even if it was all all right after 10 years and I didn't have to have it again, at least I would have been 10 years .. well you think from 42 to 75 now, those years of pain I have endured and it just progresses and progresses, it don't ease, it just gradually gets worse.* ***(75, married female, retired, previous TKR and THR)***

In contrast, two informants, despite their young age, were told they needed immediate surgery either because they would be completely immobile if left any longer, or because of the number of working years ahead:

> *Mr Q: he said, 'well you still got 15 years work left in you yet and we don't usually do this operation until people are around about'... about what age (to his wife) (W: he said you were a bit young) oh yeah, 'you are a bit young', I said 'well I am 50' , he 'oh no, it's normally round about 60'. Well that took me back when he said I was quite young like, I couldn't understand that cos being 50.. I thought 'something's wrong here', but they said 60 so I thought but he said considering you have still got 15 years work left in you, you know, and it is hurting you, so try it out.* **(51, *married male, manual worker, previous TKR*)**

On the contrary, one informant felt that his *old* age worked against him, and that ageism operated in the NHS, excluding older people:

> *Mr T: I don't like this ageism that creeping in, I am over 65 and I am expecting all the crap and put down the bottom of the list and I do believe that's what's happening cos I know one of two people who have gone in before me and I understand because they are still going to work and still supporting someone but I think you do move down a bit.* **(66, *divorced male, retired, previous operations*)**

A further two informants were told by the consultant that their old age was related to potentially serious effects:

> *Mrs K: people that have gone to see Mr 6 and especially older people and they came back and they were frightened to have their operations cos he told them he could die and therefore they were asking their doctor if they should have it done or not.. the fear is still implanted in you.* **(75, *married female, retired, previous TKR and THR*)**

> *Mrs N: he looked at me and said 'of course at your age, you know, you could finish up with clots of blood or you may not come round', so I said to me 'well none of us go before our time'.. I said 'well look I have put up with it all this length of time, I might just as well carry on and go under my own steam,'.. you know when he said I might not come round.. I said I might as well carry on and go in my own steam.. it put me off a lot.. but then when you get really bad days you think 'oh I can't put up with this for much longer'.* **(84, *widowed female, retired, no previous knee operations*)**

A small, but perhaps important group felt that the system was unfair in other ways. Three, for example, were sure that knowing or bothering the surgeon (and excessive complaining) could result in earlier treatment:

*Mrs M 'some people they keep worrying them don't they'.* ***(81, widowed female, retired, previous TKR)***

Another three were concerned that private care meant that some received unfair earlier treatment, with two believing that 'foreigners' were also seen too early. A small number of the informants (4) stated that they actually delayed the operation themselves. Reasons included fear of the operation and their perceived mildness of the knee symptoms:

*Mr U: well when I walk on it, it's not too bad, it's not that bad and I am rather reluctant to have anything done.. [wife: because I don't think he has got to the stage yet where he is desperate for it, you know you see him striding along walking, it's not too bad at all, whereas other people that we know, they can hardly move with the difficulty] you see there is no pain under my knee cap which I thought it would.. if it necessitated having an new knee joint.. it would be painful all the way round.* ***(70, married male, retired, previous hip replacements)***

*Mr X: [wife: but you weren't very keen on having an operation, you said you didn't want to have it done yet] I had a discomfort, I mean you have discomfort without a lot of pain, I thought I could probably carry on with a slight movement but then I got convinced that it would be to have it done .. convinced by others who have had it done and by the consultant.* ***(78, married male, retired, previous THR)***

## Summary

The decision to seek medical advice, the perceived view of the GPs' decision to refer and the consultants' decision to list for surgery provided an interesting insight into pathway to surgery. For example, the informants stated they were reluctant to seek medical help as they believed they could endure and tolerate their symptoms of OA. They also believed there were other people worse off than themselves and some stated that they disliked visiting their doctor. From the informant's perspective, their GP seemed reluctant to refer as they appeared to be concerned about effectiveness of the TKR procedure, were reluctant to refer less 'serious' symptoms and were more willing to try alternative remedies, rather than surgery. Finally, the informants gave their views on the listing for surgery procedure. Many felt that their age and/or weight delayed listing for surgery and believed the consultants prioritised TKR surgery in an inappropriate manner.

The next chapter explores the informants' expectations and hopes about the TKR, as well as their perception of the outcome.

# CHAPTER 7: EXPECTATIONS AND OUTCOME

## Introduction

This chapter first examines the informants' pre-operation expectations about the pending TKR. The second part describes experience of undergoing a TKR, and the perceptions of outcome as detailed from the post-operation interview data.

## Expectations of TKR

In the pre-operation interview the informants were asked to express their expectations about the outcome of their TKR. Rather than this being a simple question to answer, the informants found it very difficult to state exactly what they expected. Indeed, direct questioning about their expectations made many of the informants (16) evasive about their views:

> *I: so what are you expecting from your TKR?*
>
> *Miss D: I'm not expecting anything, I'm just going to see what happens.* ***(64, single female, retired, no previous TKR)***
>
> *Mrs M: well I don't really know until the time comes* ***(81, widowed female, retired, previous TKR)***
>
> *Mrs C: I have no idea my lovey, I am just going to plod along and I take each day as it comes* ***(63, married female, retired, no previous TKR)***

Expectations were in reality, expressed as hopes about the outcome of the operation:

> *I: what do you expect from your total knee replacement?*
>
> *Mrs I: I hope it will get better and I will be able to use it again, but that's a hope more than an expectation.* ***(69, divorced female, retired, no previous TKR)***

When expressing their hopes about the operation, the majority (18) of the informants expressed two types of hopes, which could be called 'ideal' and 'pragmatic' hopes. The former referred to the ideal outcome; the latter referred to a qualified assessment of the outcome, based on their understanding of the procedure, and their own personal circumstances. The remainder (7) did not qualify their hopes about the outcome, and

held only ideal hopes. Table 7.1 shows the relationship between the informants 'ideal' and 'pragmatic' hopes.

## Ideal Hopes

The majority stated that they *'hoped for the best'* when thinking about their operation and its outcome. This reflected their optimistic view of the operation and justified their reasons for going ahead with this major procedure. The majority were in desperate need for surgery and viewed the TKR as the 'last resort'. They 'pinned all their hopes' on the operation. The main 'ideal hopes' held by all the informants were the complete relief of pain and increased mobility:

> *Mr Q: hope to get rid of all the pain… if it meant getting rid of all the aching and the pains and all the rest of it.* ***(51, married male, manual worker, previous TKR)***

> *Mr X: well I am hoping I will be able to walk in a routine manner without this thing flopping around. It stops you walking properly, you have got to limp more. I am hoping to be able to walk in places I can't walk at present because my knee would give way.. that's how you feel all the time..* ***(78, married male, retired, previous THR)***

As a result of their 'hoped for' improved pain relief, one informant hoped to walk without a limp, and a further four informants wanted to be able to walk without their walking sticks after the operation. Added benefits of the pain relief and increased mobility also would mean (for five of the informants) that they would be free from worrying about the knee and the cautiousness needed when doing normal activities:

> *Mrs M: I hope to be free from thinking about my bad knee and that.. well you know you have got it, it's at the back of your mind, I mean I go along very carefully, I mean I wouldn't like to fall down cos I wouldn't like to think what he consequence would be.. so I take jolly good care if I can.* ***(81, widowed female, retired, previous TKR)***

In addition, a further three informants wanted to lose weight after their operation:

> *Mr Q: get all this down, all this weight off because if I wants to do something, I can't because I am restricted in what I do.. because everything is either arms or legs, I have put too much weight on.. so that's what I would like to do.* ***(51, married male, manual worker, previous TKR)***

*Table 7.1 'Ideal hopes' and 'pragmatic hopes' of the informants*

| Informants | Ideal hopes | Pragmatic hopes |
|---|---|---|
| Mrs A | Pain free. Increased mobility. Go on holiday. Back to sports. | |
| Mrs B | Pain free. Increased mobility. Normal activities. No painkillers. No walking aids. DIY. Look after/play with grandchildren. | Major operation - cannot expect complete pain relief. Uncertainty about the unknown. |
| Mrs C | Pain free. Increased mobility. | Complications. Uncertainty about the unknown. Co-morbidities. |
| Miss D | Pain free. Increased mobility. | Complications. Co-morbidities. Doctors not miracle workers. Not complete pain relief- major operation |
| Mrs E | Pain free. Increased mobility. Not be a burden on anyone. New lease of life. Better quality of life. Free of worry. Go shopping in town. Look after/play with grandchildren. Independence. | Lack of faith in the NHS. Major operation - cannot expect complete pain relief. |
| Mrs F | Pain free. Increased mobility. Independence. | Complications. Doctors not miracle workers. Major operation - cannot expect complete pain relief. |
| Mrs G | Pain free. Increased mobility. Independence. Go on holiday. Go shopping in town. | |
| Mrs H | Pain free. Increased mobility. Independence. Look after/play with grandchildren. Go shopping in town. | |
| Mrs I | Pain free. Increased mobility. Normal activities. Better quality of life. Lose weight. | Doctors not miracle workers. Uncertainty about the unknown. |
| Mrs J | Pain free. Increased mobility. Normal activities. Better quality of life. Independence. No painkillers. | Complications. |
| Mrs K | Pain free. Increased mobility. Better quality of life. Free of worry. | Complications |
| Mrs L | Pain free. Increased mobility. New lease of life. Free of worry. Travel to see family. | Co-morbidities. |
| Mrs M | Pain free. Increased mobility. Normal activities. Better quality of life. Free of worry. | Age. Uncertainty about the unknown. |

*Table 7.1 'Ideal hopes' and 'pragmatic hopes' of the informants (cont'd)*

| Informants | Ideal hopes | Pragmatic hopes |
|---|---|---|
| Mrs N | Pain free. Increased mobility. Not be a burden on anyone. New lease of life. Better quality of life. Lose weight. Independence. Go on holiday. Go shopping in town. Travel to see family. | |
| Mr O | Pain free. Increased mobility. Stiffness relief. Back to work. Normal activities. Back to sports. No limp. No walking aids. | |
| Mr P | Pain free. Increased mobility. Stiffness relief. Free of worry. | Uncertainty about the unknown. |
| Mr Q | Pain free. Increased mobility. Back to sports. Better quality of life. Lose weight | |
| Mr R | Pain free. Increased mobility. Play golf with friends. | Doctors not miracle workers. Age |
| Mr S | Pain free. Increased mobility. New lease of life. Look after/play with grandchildren. No walking aids. | Delayed surgery. Ingrained beliefs about prosthesis. Bad previous experiences. |
| Mr T | Pain free. Increased mobility. Normal activities. Better quality of life. | |
| Mr U | Pain free. Increased mobility. Gardening | Other health problems more important. Heard of unsuccessful TKR outcomes. |
| Mr V | Pain free. Increased mobility. Normal activities. | Major operation - cannot expect complete pain relief. Complications. |
| Mr W | Pain free. Increased mobility. Independence. | Did not want to tempt fate. Co-morbidities. |
| Mr X | Pain free. Increased mobility. Better quality of life. | Co-morbidities. |
| Mr Y | Pain free. Increased mobility. Gardening. Travel to see family. Normal activities. Back to sports. No walking aids. | Age |

Two informants also wanted stop taking their tablets after the TKR:

> *Mrs J: I hope so, I hope that I can come off of those… I think there will be no need to take the tablets, you know it would be brilliant, wouldn't need to take them.* ***(71, married female, retired, previous TKR)***

Another 'hoped for' consequence of pain relief and increased mobility was that this would (for 19 of the informants) inevitably lead to an improved quality of life; they would be able to live a 'normal life' again. Three informants actually hoped that the outcome of the TKR would give them a *'new lease of life'* and make them a *'completely different person'*. Returning to sporting activities (5), to play with grandchildren (4), shopping (4), holidays (3), gardening (2), visit family (3), and DIY (1) were all activities that the informants wanted to do normally and without any restrictions after their TKR:

> *Mrs F: get on with my life, that's all I want to do, just get on with my life, I mean whatever the span is, or what is going to be in front of you.. it is nice to think that you are moving in the right direction and I hope to be more mobile.* ***(65, married female, retired, previous TKR)***

> *Mrs I: I would like to be able to swim, I would like to be able to get in and out of the pool and I would love to be able to go into the sea again but at the moment I am scared, I mean that would be plain stupid, you know.. and I don't sort of want to go mountaineering or.. so quality of life is being active and being able to do the things you want to do.* ***(69, divorced female, retired, no previous TKR)***

Seven of the informants explicitly stated that they also wanted to regain their independence and a further two stated that they did not want to burden friends and family:

> *Mrs J: It's the independence and you want to be independent, you don't want to rely on other people, you know I've never never relied on other people, I mean I've always helped other people.* ***(71, married female, retired, previous TKR)***

> *Mrs N: I mean have a bit more independence, not wait for someone to come and pick me up and if I feel like going out I should be able to go out, if it was a nice day I won't have to sit here, you know.. being able to get myself ready and go out and I have friends around the country that they are always asking me to go.* ***(84, widowed female, retired, no previous knee operations)***

## Pragmatic Hopes

Eighteen of the informants did not actually think their ideal hopes could be achieved. They gave a variety of reasons for this and came to a more pragmatic view of the TKR outcome. In effect, they qualified their expectations/hopes to be more realistic. The remaining seven informants who did not qualify their hopes, tended to view the TKR as a 'miracle cure'.

The majority (14) of the informants expressed some reservations about achieving their ideal hopes. They anticipated that the operation would improve their condition but would not be a miracle cure as hoped:

> *Miss D: I don't think it will be as new as new.* ***(64, single female, retired, no previous TKR)***

> *Mrs B: well I'm hoping it will make me more mobile, I doubt if I will get back to the way I was.* ***(62, married female, retired, no previous TKR)***

Reasons for caution included fear of the unknown (5):

> *Mrs I: I have never had a knee done before so I don't know how it will go.* ***(69, divorced female, retired, no previous TKR)***

> *Mrs M: well I don't really know 'til it happens do I.* ***(81, widowed female, retired, previous TKR)***

> *Mrs B: well I've never actually had an operation put it that way for anything at all, I don't consider having children an operation and that wasn't terribly frightening, I mean you hear horror stories about having babies but I don't think it's all that terrible, so I don't know what will happen, what to expect.* ***(62, married female, retired, no previous TKR)***

Other factors included the fear of 'tempting fate'(10):

> *Mr W: I don't think it's going to be 100 percent, that's too much to ask for .. don't want to tempt fate and ask for too much.* ***(78, widowed male, retired, no previous knee operations)***

Three informants felt that they would not fully recover from the TKR because of their 'old' age. The TKR could not completely reverse the damage that wear and tear over many years had done to their knee joint:

*Mr R: obviously the pain and the discomfort will be relieved a bit but I'm not expecting miracles, no I wouldn't expect too much especially at my age and as I say I doubt that the old joints are never going to be the same as they were.* ***(59, married male, retired, previous knee operations)***

Six informants had knowledge of potential problems that can occasionally arise from TKRs, from others' experiences:

*Miss D: well I don't really know when they say it doesn't always work, I mean with my foster son he was told that if the body doesn't accept the joint or whatever, whatever reason that happens erm that they would just freeze the knee so he would just have a stiff leg.* ***(64, single female, retired, no previous TKR)***

*Mrs C: if they put cement or whatever they are going to do there and seal it all up, well will that wear away and rub and that, that's what's worrying me, will it rub, will I be in a lot more pain after ... no one knows do they and they don't know how the nerves are going to be.* ***(63, married female, retired, no previous TKR)***

Five informants felt that their other health problems may affect the outcome of their TKR:

*Mrs C: probably only be mobile in the house but I don't know about outside because of the other knee.. when it's just one knee and everything else is all right, it would probably be different but as I have got it everywhere, I really accept that there is always going to be problems around somewhere.* ***(63, married female, retired, no previous TKR)***

Four informants expected a certain amount of pain from the operation, as a result of the actual surgery:

*Mrs F: but no I don't say it is going to be pain free, I would think there was something wrong if it was pain free.. not enough to get in a state about it but I would think everyone would say the same, that all right you have and you expect some discomfort from it, why shouldn't you cos I mean they pull and hack you around enough.* ***(65, married female, retired, previous TKR)***

## TKR as a 'miracle cure'

As stated, seven informants did not qualify their hopes and continued to hold their 'ideal' hope that the TKR would result in complete pain relief and improved mobility. As a result, some viewed the TKR as a 'miracle cure':

*Mrs J: it's a miracle cure really it is, I mean I would have still had it in this knee if I hadn't had it done so it is a miracle cure isn't it* ***(71, married female, retired, previous TKR)***

*Mrs G: I think it's going to be like a miracle cure.. the pain and then more mobility... brilliant.* ***(68, married female, retired, RA and SLE, previous TKR knee operations)***

Mrs J, although confident about the success of TKRs, also viewed 'second' TKRs with more pragmatism, as she believed they were more problematic and complicated than primary TKRs. Although this view may be confused with revision TKRs (which are notoriously known as complicated procedures), Mrs J did not know whether she would be so lucky this time. However, she stated that because she was positive about the operation and had good healing skin, this would be unlikely:

*Mrs J: it's a miracle cure really it is, I mean I would have still had it in this knee if I hadn't had it done so it is a miracle cure isn't it.. but I'm still a bit apprehensive because I have heard people who have gone in for a second one and they have had complications and I think am I going to be so lucky the next time but I don't know, I have heard they are more advanced, I don't know are they more advanced in 6 years, I don't know I suppose it's... it's probably the whole attitude you take to these things, I mean if you take a positive attitude I suppose things can turn out a lot better. But that's only one incidence, out of the thousands who have have it done.* ***(71, married female, retired, previous TKR)***

## Pessimism

There were three informants who, although they expressed ideal hopes, were very pessimistic about the operation and did not anticipate any success:

*Mr U: I really don't think it is going to be any better.* ***(70, married male, retired, previous hip replacements)***

*Mr S: I don't have no hope.* ***(64, married male, retired, previous knee operations)***

The first informant, Mr U, viewed his muscular pains as more important and more painful than his joint problems, and thus felt that they needed treating before the TKR could be successful. Quite simply, he believed the surgeon's priorities were wrong and felt his muscular problems should be dealt with first:

*Mr U: I really don't think it is going to be any better.. it seems to me that we are putting the cart before the horse really.. I ought to have*

*my rheumatic or arthritic conditions dealt with before the knee replacement, like I say I don't think it [TKR] will be any good without doing that... if I could get rid of these arthritic pains there [thigh, back of leg].. I would get rid of that pain there [knee] and things would be better.* ***(70, married male, retired, previous hip replacements)***

He had also heard of negative results from other people's TKR outcome:

*Mr U: is it going to be a success or not, because up until.. my cousin has just had it done.. I have known 4 people who have had knee replacements and they have been more or less a disaster and I am always a bit.. one person I know of she has had about 4 put in and someone else that I know has had it replaced twice so it leads me on to wonder whether it's.. you know you just don't know if it's going to be a success or not.* ***(70, married male, retired, previous hip replacements)***

The second informant, Mr S, felt that as his knee had been left untreated for so long, the damage was too severe and there was little hope of success:

*Mr S: I am not very hopeful, I don't think it will be very successful, not now it has been left for so long, it's so bad now.* ***(64, married male, retired, previous knee operations)***

In addition, he believed that a man-made prosthesis could never function or surpass the mechanism of the human knee joint:

*Mr S: I mean all they can do is put in a man made knee hoping it will do the job the same.. it won't do the job the same because nobody can replace anything that God has made, no man, no doctor or scientist, however clever.* ***(64, married male, retired, previous knee operations)***

The third informant, Mrs E, was very negative about the success of the TKR due to her lack of confidence in the NHS in general:

*Mrs E: I am so apprehensive, I don't think it's going to be a success.. I have no faith in them, not now.. well it's because, to be quite honest with you, too much knowledge sometimes is a dangerous thing and you have got the media hype, you have got the papers and in all fairness the National Health has gone down hill dreadfully. I mean last week you heard of neuro surgeons won't perform operations on patients that are at risk because they are frightened of being sued and things like that so it's not giving you confidence is it, I don't know at one time you trusted your doctor, like your parish priest, you trusted everybody but oh I don't know, there is no confidence.* ***(64, married female, no previous TKR)***

Part of this lack of faith stemmed from a fear of medical negligence. Mrs E had read in the newspapers that individuals had found 'do not resuscitate' (DNR) on their notes, without having had discussion or prior knowledge about this. She was extremely worried about this may happen to her and believed the consultants were performing 'backdoor euthanasia' on older people:

> *Mrs E: my fear is having DNR on my notes, that's my biggest fear, I have a right to my life but I feel that er you know we are practising quite honestly, and I will say this with all sincerity, euthanasia through the back-door, that is my honest opinion, that us old ones, you see we have contributed for years with our social security, our national health stamps or whatever stamp we paid for years to keep the next generation in the social security, but what I am saying is, we have never been a drain on society, we have paid our stamps, but we are a drain now because we are pensioners, surplus to requirements.. and I feel that it's euthanasia through the back door, that if they take you in, operate on you and if there is a little blip that comes up, write that one off... it's just the whole structure of the NHS, do you see what I am saying, I mean I honestly believe it is euthanasia through the back door and that's what scares me more than anything cos I mean I am 63, I think as though I have got another ten years or more and why can't I have that ten years, why should I just pop my clogs and I mean I have only been retired a couple of years, why can't I enjoy a few more but I just think it is so sad the way everything has gone.* ***(64, married female, no previous TKR)***

## Fears

The majority of informants (19) expressed either one or several specific fears about the operation and recovery process. Those fears appeared to be independent of their hopes. For example, of the seven informants who expressed only ideal hopes, five also expressed fears. Similarly, of the 18 who expressed pragmatic hopes, 14 expressed fears about the operation. Therefore neither the 'ideal' nor the 'pragmatic' group had any greater tendency to express fears. The main fear was related to the anaesthetic (16), such as surviving the anaesthetic (8), sickness (3), or waking up during the operation (3):

> *Mrs L: that's what I dread.. that I don't come round and my son and my daughter say 'well you won't know nothing about it' but I don't think like that.* ***(80, widowed female, retired, previous THR)***

> *Mrs C: I do not like it, I'm sorry love but I have had so many problems with the anaesthetic and I think a lot of it goes back to when I was thirteen when I had my tonsils out at hospital 10 and I didn't like it then, what I can remember is my mum took me up and there were big open fires in the wards then and we sat on the carpet by the fire but the*

*worst thing I can remember, worse of all was having to take tablets with a bit of jam on them and then the mask they put on over your nose and mouth and they have to count right down, the anaesthetic I suppose, ohh that was horrible.. I can remember that very well, that's the problem, I can remember things that go back a long time, it's that mask and the after-effects, feeling so sick afterwards and being sick and urging and urging.. oh it's horrible, every time I have had the anaesthetic, even when I had the injection at the bottom of the spine, I was sick, and I don't like being sick.. I am a great coward of being sick, I am really.* ***(63, married female, retired, no previous TKR)***

> *Mr T: and I don't want to wake up or nothing, you hear all sorts of stories but that only happens once in a million or something.* ***(66, divorced male, retired, previous operations)***

Other fears included ending up with a stiff leg (5), rejection of the joint (2), risk of infection (1), heart failure during the operation (1), or risk of thrombosis (2):

> *Mrs B: the only thing that has bothered me is the fact that they say it doesn't happen very often but you can get blood clots which they worry about don't they and someone I know who has just had one, ..it's just the fact that you could get blood clots and it could cause problems but I don't see why it should cos I've got no problems with my blood pressure or anything like that.. I think he was telling me, I think he must tell everybody that there is the possibility of this but it's very very rare but you know you have always got it in the back of your mind, you think it might be you.* ***(62, married female, retired, no previous TKR)***

Four informants expressed a wish to have an epidural rather than general anaesthetic. This was in relation to co-morbidities that the informants had, such as high blood pressure:

> *Mr W: instead of having an operation when they send you right out, why don't they freeze part of your body then do it.. say somebody's blood pressure has gone high, then they could have a freeze.. well my daughter reckons they do, someone had theirs done and they froze them from your body down, I suppose it's possible.* ***(78, widowed male, retired, no previous knee operations)***

## Outcome preference - pain relief or increased mobility

As stated above, it was difficult for the informants to express any 'expectations' about the outcome of the TKR. However, it was found that when they were asked hypothetical questions about their outcome, they were better able to articulate what they would prefer. For example, during the interviews, the informants were asked for their

preferred choice between 'being more mobile but still experience the pain' or have 'less mobility but without pain'. Thirteen of the informants said they would prefer mobility over pain relief, five reported they would prefer pain relief, and the remaining seven found this question impossible to answer because they either strongly desired both or felt that they could not be separated.

Increased mobility tended to be preferred by those informants who either lived alone or were intending to return to work. Five informants felt they had got used to the pain and were able to control it:

> *Mrs C: probably more mobile, if you have got a dull ache you can put up with that, I have had it so many years I have accepted it.. this is it, you just accept it, that's how it is with you, I mean I have had it years I really truly don't know different.. but it's getting round and being mobile that is more important* **(63, *married female, retired, no previous TKR*)**

A further five informants found their present immobility frustrating and wanted to return to normal activities:

> *Mrs B: I would rather be mobile I think, cos it gets very frustrating especially if you can't do things that you want to do.* **(62, *married female, retired, no previous TKR*)**

The fear of ending up with even more immobility and being reliant on others was raised by three of the informants:

> *Mrs I: I think I would choose the mobility, yes just to.. I fear immobility, I really fear not being able to get out because in a place like this if you are stuck in all the time then you get miserable but if you can get out.. the old saying.. 'get a life', if you can keep your interests going.. the thought of sitting in here day after day and not being able to do anything, well I don't want to know.. so it's the independence.. but I fear having to rely on other people, I do fear that but I push it to the back of my consciousness .... If you start fretting and worrying about it you are half way there* **(69, *divorced female, retired, no previous TKR*)**

One informant, who cared for his wife, wanted to be more mobile in order to look after her:

> *Mr V: oh more mobile and I could deal with the pain. I need to care for my wife* **(74, *married male, retired, previous TKR*)**

The five informants who said they would prefer pain relief stated that this was due to the tiresome and depressive effects of pain:

> *Mrs L: the pain I think, to be honest with you, I know you want your mobility, I know that but the pain wears you right down, cos I have always said if it wasn't for the pain I could put up with it.* ***(80, widowed female, retired, previous THR)***

Seven were unable to answer this question, as they could not separate the two choices: they believed they were inextricably linked:

> *Mr X: well one goes along with the other.. I mean I wouldn't separate them really, I shall be hoping that I will have less pain and more mobile, that's what I am looking for.. I want mobility and I want less pain..* **(78, *married male, retired, previous* THR)**

> *Mrs E: at this moment in time, mobility and pain cos of my views on everything.. well it's a catch 22 isn't it, I mean there is nothing worse with being immobile and being a burden on someone or being in pain and just shuffle about.. it's one really you can't answer because no one wants to be in constant pain but then again I don't want to be immobile either and be a burden on anyone.. I want both, of course I do, it's like I said to my eldest daughter, I said if I am in a road accident and you know I am not there, I am not with it, put a pillow over me and get rid of me cos I wouldn't want any of my children.. they have worked too hard and they have got their lives to sort of have us to struggle around, you know* ***(64, married female, no previous TKR)***

## Summary of pre-operation hopes/fears

It was clear that informants found it difficult to indicate clearly their expectations of TKR. They found it easier to discuss their hopes and fears about the operation, rather than give definite views on what they expected. All had an 'ideal' hope but most also had a more realistic view taking into consideration their knowledge and personal circumstances. A range of reasons led the informants to hold a particular view on the likely outcome of the operation, including lay beliefs, personal experiences, and experiences of friends and family. Most had specific fears about certain aspects of the surgery and recovery. Stating a preference about the possible outcomes appeared was easier for the informants to express.

## Experience of a Total Knee Replacement

Ten informants were interviewed again approximately six months after their TKR. The following results relate only to the post-operation interview data. The TKR as experienced by the 10 informants is briefly outlined examining issues concerning the 'admission' to hospital, their 'inpatient' stay and their experiences 'after discharge'. Many of the issues highlighted reflected the informants' TKR fears stated at the pre-operation interview, discussed in the previous section.

### Admission to hospital

Some aspects of the admission procedure frustrated the informants. Half of the informants (Mrs M, Mr O, Mr P, Mr S, Mr T) had problems with finding an available bed. After telephoning several times, three informants, even in the hospital, still had to wait in day rooms until an available bed was found. This was perceived to be very inefficient and the informants felt that as they had been on the waiting list for so long, it really should have been organised earlier:

> *Mrs M: [field notes] The receptionist at the hospital said that there might not be any beds available. However, Mrs M had already arranged transport up to the hospital so was told to come up and see what happened. Mrs M said she was put in a day room from 12 o'clock until 8 o'clock at night before they found her a bed and she found this very unsettling. She felt 'hard done to' as she felt the hospital should have sorted this out before the day of her operation – after all she had 'been waiting for two years' for the operation.* ***(81, widowed female, retired, previous TKR)***

The risk of losing the allocated bed once in hospital caused one informant to stay an extra night in hospital prior to the operation, even though he was told he could go home (his operation had been delayed for a day):

> *Mr T: I unpacked all my stuff and I put it all away and he said 'we won't be able to operate tomorrow, so you can go away if you want and you can come back tomorrow'.. and I said yeah that's fair enough so I started to pack my stuff up and some bloke told me in the ward that it wasn't sure if I would get this bed again tomorrow.. I said .. so I asked the nurse, I said 'am I sure to get this bed tomorrow', and she said 'no, when you turn up that bed could be gone'.. so I was angry.. I said 'I have been waiting over a year for this operation, almost two years', I said 'I'm staying the night, I ain't bloody moving, I am in the bed and you will have to feed me, I ain't going nowhere'.* ***(66, divorced male, retired, previous operations)***

Seven of the informants did not experience any delays in their operation. For the remaining three informants, their operation date was postponed because of bed shortages or unforeseen circumstances. For example, on the day Mrs J was to have her operation, there was power-cut in the hospital and all operations were cancelled for that day. Unfortunately Mrs J had already been anaesthetised, and so when she awoke from the anaesthetic, she had to be told that her knee had not been replaced. She had to go home and return a week later. Although disappointed, she accepted that it was unavoidable:

> *Mrs J: oh disappointed, naturally especially having the premed and anaesthetic but it was no fault of theirs, it was just one of those things.. I went off to sleep and of course I came round and nothing had happened and I thought Good Gracious, I thought it was all over.* ***(71, married female, retired, previous TKR)***

Another informant, Mr O (who had the pre-operation treatment to try and straighten the leg), had to persuade the consultant to perform the TKR. Due to his young age and the limited life span of the prosthesis, the consultant wanted to fuse the leg, rather than replace it. This was a similar conversation they had had over a year ago, when Mr O was put on the list. Mr O insisted he wanted the quality of life now, and thus wanted a TKR rather than a stiff leg. The consultant finally agreed to go ahead with the TKR:

> *Mr O: what he offered to do and he was still trying to talk me into that was to straighten the leg so I would have no joint… he explained about the life span of the joints and so forth.. and then in 20 years time he would give me a joint so I could have quality of life in 20 years but that was ridiculous, but I said that I would rather have the quality of life now so that I can actually work.. do some work and then in 20 years time if I have to slow down at work or pack in working then at least I have had the chance to work and earn a pension and take care of my kids while they are young, you know what I mean, and then later on it will be just me and my wife and if that's what happened so be it so I wasn't prepared to have a straight leg at all.* ***(40, married male with family, on disability allowance, previous knee operations)***

## In-patient stay

For six of the informants, one of the major fears about the operation was the risk of not surviving the anaesthetic. However, once in hospital, the informants were told that rather than have a general anaesthetic they would be given an epidural instead. These informants welcomed this information:

*Mr P: I would go for the local anaesthetic, the epidural, anytime… cos you feel that.. well you are not in control but you knows what's going on. I was awake all through the op, and they started putting all the sheeting around so you can't see what's going on down below and that and I was laid there sort of looking around and all of a sudden I seen this foot floating above the sheets, I seen this foot floating above and I thought 'what's that.. why that's my foot'.. but I couldn't feel it, my brain was telling me that I was still laid out flat but I seen this foot up in the air and I couldn't believe it, you know.. it was a real weird sensation and then er.. they just carried on and done everything so they.. gave me some ear phones with a bit of music to listen to but even with that on I could still hear the drills and like the grinders and all that sort of thing.* ***(48, single male, on disability allowance, no previous TKR)***

After surgery, the informants were taken to a recovery room where they were monitored. Although pleased that the operation had been completed, four informants (Mrs B, Miss D, Mrs J, Mrs L) were sick from the anaesthetic. Two (Miss D, Mrs J) had expected to feel sick due to previous experience, and knew it was only temporary. Mrs B, however, had a fear of being sick, and believed it was her fault as she had sipped some water with her pre-medication, when she had been told not to drink or eat anything:

*Mrs B: but I was sick, it was just fluid but I am terrified of being sick.. I don't know but it's something I have always had ever since I was a child I think.. they put you out and they gave me a sedative, or something and then you get the anaesthetic don't you, put into your hand once you get down there, and I don't remember anything except when I was coming round in the recovery room and I was sick afterwards but I think that was because when they gave me the tablet, because I took a tablet to, I don't know, they were sort of trying to calm me down, I took it with water.. whether that had anything to do with it or not, because you are not supposed to drink or eat before the op.* **(62, *married female, retired, no previous TKR)***

An important aspect for eight informants concerned the appearance of the wound immediately after surgery. The unexpected fact that their knee was 'stapled' together rather than 'stitched' caused these informants alarm:

*Mr T: I wasn't too happy with these steel clips, when I saw them, well it was an absolute disaster, when I saw all these steel clips, I thought, what on earth…I didn't know I was going to have them I thought it would be sewn up, and then when he was going to take them out, I thought 'how on earth will they take these out', what are they going to do, get pliers on my leg.* **(66, *divorced male, retired, previous operations)***

However, once the staples had been removed (without difficulty), six of the informants commented on how neat their scar was and how they associated this with good surgery and a good recovery:

> *Mrs E: having a neat scar helps you get over the recovery, makes you feel like you have had a good job done... it is a neat scar and if you look there, you see it is beginning to fade look, in parts, so yeah I felt he did quite a good job.* ***(64, married female, no previous TKR)***

The relationship built with the other patients on the ward was discussed by nine of the informants. Eight stated that there was an *'innate humanity'* which surfaced very quickly, even spontaneously, between themselves and other patients:

> *Mrs J: I mean you have a happy time really and you meet other people and other patients as well, and get a sort of liaison between each other and it's really pleasant.. yeah well they are in the same position as me.. the lady that was in the bed opposite me, we had quite a good rapport between us, she was quite a nice lady.* ***(71, married female, retired, previous TKR)***

Mrs E, however, who did not have a rapid recovery, found it frustrating observing others who were improving quicker than herself:

> *Mrs E: I mean some of those in that age group put me to shame really because they were wonderful, absolutely wonderful, they put me to shame.. there was a man there, he had both his knees done, and he was sat there and he was giving it all this, swinging his knees and I thought 'ooh' and he was swinging his legs and I said to my daughter 'oh look at him, he is getting on my nerves' the way he was throwing his legs about like.. I thought 'oh my godfathers, how wonderful' and this woman I was in with I mean she was 80 and she was curled up like a ball with her legs up and I thought 'oh isn't that wonderful, to sleep on your side with your legs up'.. and she had only had it a couple of days after me and she was all tucked up and it looked wonderful.. here's me with my poor knee.* ***(64, married female, no previous TKR)***

Informants were keen to discuss their satisfaction with the standard of care. Six informants found the staff welcoming and caring (Mrs B, Miss D, Mrs J, Mrs L, Mr O, Mr P):

> *Mr O: they were brilliant, they were fantastic, every time I have been in the staff have been really good, I mean I know they are being paid to do a job but you actually feel like they care and they were very sympathetic.* ***(40, married male with family, on disability allowance, previous knee operations)***

However, another three informants found the staff unhelpful. Two of these informants (Mrs E and Mr S) generally had negative views of the NHS and had experienced bad incidents in the past:

> *Mr S: but the attention from all the young nurses.. they seem to mess around a lot to what they used to.. but I must admit the sister was away, the sister of the ward, she was on holiday and there was this other woman in charge but you couldn't.. they were a little flighty, some of the young nurses and young male nurses.. as far as I was concerned they should have took more interest and shown a proper picture of what it should be in nursing to the patients, but they didn't, they were very flighty* ***(64, married male, retired, previous knee operations)***

Mrs E and Mr S also discussed the lack of hygiene of the hospital:

> *Mrs E: I mean cleanliness, I think was a big major fall-down on the.. I mean you go into the loo and I mean it was soiled and it stayed that way for days, do you know what I mean, because you tend to keep using.. the same avenue as you like because you are restricted with your walking and I got into a shower one day and it was all broken and it stayed that way, you know what I mean, nothing got repaired or things like that, it's so sad.* ***(64, married female, no previous TKR)***

A minority of the informants (Mrs B, Mr P) stated that they had to have blood transfusions after the operation. Both informants felt uncomfortable about this. Mr P was worried about the potential diseases in blood whereas Mrs B just did not like the idea of having someone else's blood inside her. They were both relieved when their own blood was recycled.

The view of the consultant was discussed by the informants, most of them reiterating their pre-operation perceptions. For example, most stated that they had complete faith in their consultant's expertise, and they found their consultants more approachable and friendlier than in the past. However, the informants had complaints about the consultant due to their perceived absence (5), or poor bedside manner:

> *Mrs B: he didn't say anything to me, he was talking into a recorder thing, yeah, and they don't seem to write anything down these days.*
> ***(62, married female, retired, no previous TKR)***

The status and the experience of the consultant were important to two informants. For example, Mr S felt safer knowing that the 'top consultant' operated on his knee:

> *Mr S: I was told from the beginning that he [senior consultant] was going to do it and I had accepted that in my mind, and that made it a lot easier, and that's why it went so well, I believed in myself, and my*

*body must have known, I'm not being funny but even the knee must have known, from the brain, the brain is not dead in operations, it's going down to tell the knee to behave itself, Mr 1 is doing it.. it might sound funny but it's true.. so things went well, very well.* ***(64, married male, retired, previous knee operations)***

Mr T, however, explicitly stated that he felt that senior consultants were 'glory-takers', in that they took the credit for the success of the operations without actually performing them:

*Mr T: Mr 1 didn't do it, an Indian done it … he came round with Mr 1, Mr 1 was doing all the chatting because he is head man, and I said 'who done this', and he said Mr so and so, well he wasn't going to tell me this, I said 'I am chuffed with my knee'.. so I found out that it wasn't Mr 1, even though his name is up on the board.. he was out playing golf or something I suspect, when he was supposed to be on me, working on me… now he is the top man, he takes all the credit and all the money and there is the underbloke, they are doing all the work and all that, with no credit… I was quite pleased with the bloke [junior consultant] who done it, and I think they [senior consultants] are a little bit.. what's the saying… familiarity breeds contempt.. you just do the same old thing and he'll be chatting while doing the operation and 'oh that'll do', whereas with a young doctor he is really doing his best and he is trying to get on, he don't want no black marks on his book because he wants to get where Mr 1 is.. and he is one of maybe 4 or 5 fighting for position on that team so they are more conscientious.. just as long as he had done them before, I don't want them practising on me.* ***(66, divorced male, retired, previous operations)***

The information provided at the hospital was thought to be sufficient by only one informant (Mrs J). However, another five (Miss D, Mrs B, Mr T, Mrs M, Mrs E, Mr P) thought it was inadequate:

*Miss D: nobody really said what you are supposed to do or not to do.. well they like you out of bed apparently.. but no-one actually told me.. and it's all very fine sorting out how you are going to manage but nobody tells you how to get into the car, you have got two sticks, you have got a leg which is very difficult to move and you are expected to go home in a car, somebody has got to take you home but nobody explains how to get in the car.* ***(64, single female, retired, no previous TKR)***

The majority of the informants (7) were aware of the life span of the prosthesis, although the perception ranged between 10 and 25 years. Two informants (Mrs E, Mrs B) were already worrying about the likelihood of having future revision operations. This fear delayed the informants discussing the possibilities of their other knee being replaced, as they did not want bilateral operations when they were older:

*Mrs B: I'm glad I have had it done but I don't know whether I would go in and have my other one done.. because they only give it about 15 to 20 years don't they.. and I would.. I think I would like to wait, cos this one is not really very bad and will go a little bit longer before I.. because you would have both of them practically going at the same time I should imagine.. hopefully I am going to live another 20 years and I suppose it will have progressed a lot more in a few years time so erm.. if I waited and had this one done later on, maybe it would be, you know, you wouldn't have to have it done again.* ***(62, married female, retired, no previous TKR)***

Seven informants discussed how they felt about having a man-made prosthesis inside them, which again tended to reflect their pre-operation views. Five of the informants viewed their prosthesis as a 'part of their body' and did not feel it was separate from their body:

*Mrs M: Mrs M said that she was not bothered about the prosthesis as she doesn't not think about it as being any different..' I just sort of.. I know its being done and that's how you accept it'.* ***(81, widowed female, retired, previous TKR)***

*Mr T: no doesn't bother me, that's all part and parcel of it, doesn't enter my head* ***(66, divorced male, retired, previous operations)***

However, two were upset by the idea. Mrs B did not like the idea of being 'bionic', whereas Mr S disliked the idea due to his Christian beliefs:

*Mr S: I thought that knee was Christian.. it was put there by God, to me it was sacrilege… I told my doctor this, he is very religious, and he knew what thoughts I had and he agreed, but he said you have to put it into perspective, you have got to think a positive way in life and that's the only way you can go about it, and he was right.* ***(64, married male, retired, previous knee operations)***

All ten informants reported that physiotherapists provided and demonstrated certain exercises for the knee to regain the range of movement. The role of the physiotherapist also extended into providing advice about medication, and two informants viewed them as aggressive in the attitudes towards exercises:

*Mr O: the physiotherapists.. or physioterrorists.. [laughs] they were good, very understanding.. they are hard the physioterrorists.. they are hard but they do a bloody good job, an excellent job.* ***(40, married male with family, on disability allowance, previous knee operations)***

A minority were critical of occupational therapists, feeling they were only beneficial for patients who had had total hip replacements (Mrs B) or for the elderly infirm (Miss D, Mrs J, Mr P):

> *Miss D: then the occupational therapist keeps running around but they are obviously geared to the elderly infirm.* ***(64, single female, retired, no previous TKR)***

One informant felt humiliated when asked to demonstrate that she was able to go to the toilet unaided, which she felt was unnecessary:

> *Miss D: she said 'well would you like to come along to the kitchen cos I need to now see that you can cope with making a cup of tea' and I said 'well I was doing that right up to the time I came in here and it's better now, I am going to find it easier now than I did before I came in here' and I said 'no I don't think there is any need to do that' but she said 'well are you quite sure because I am supposed to see that you can do it'. I said 'well I can do it' and I said 'if I get really in a mess I've got people that I can get hold of quickly', I found it very humiliating.. 'well are you quite sure about that.. well I will have to see that you can cope with the toilet'.. so I said 'well I have been doing that since Sunday'.. but she had to see so we go along but the odd thing about it was I sat down and she said 'oh yes I can see that' and turned and walked away.. well it's not sitting on the toilet that's the problem, it's the getting up that's the problem but she didn't stop to see that.* ***(64, single female, retired, no previous TKR)***

The remaining six informants did not seen to be aware of the role of the occupational therapist.

## Discharge from hospital

The length of time the informants spent in hospital varied from five to 14 days: the average being ten days. The majority of informants were pleased to be discharged and return to their home after being in hospital:

> *Mrs J: I was glad to get back.. you are always glad to come out, I mean you are glad to go in and get your operation and get over it but you are always glad to get out.. or twice as glad to get out really.* ***(71 old married female, retired, previous TKR)***

In fact, Mr T insisted on being discharged after only five days in hospital, the reason being that he was worried about the risk of infection:

> *Mr T: I got out of hospital so quick, they tell you to walk up and down steps, stairs like, on your sticks, down stairs.. get the 90 percent flexion.. well I done that under great pain but I was determined to get*

*out of there.. I didn't like it .. they had those infections across the ward, they worried me, I wanted to get out of there and I did.. I was out of there so fast.* ***(66, divorced male, retired, previous operations)***

On the contrary, Mr P, who remained in hospital for seven days, felt that he had been sent home too early, as he still felt ill after the operation and had difficulty coping:

*Mr P: I think I should have stayed in hospital longer because I was burning up quite a bit.. when I got home I was rough for a few days afterwards, it was a bit of a struggle when I got home really.. but I got over it, it was more difficult because I was just stuck in here on my own and I couldn't do nothing.. if my dad had still been here, it may have been different.* ***(48, single male, on disability allowance, no previous TKR)***

Another informant (Mrs B) felt peculiar coming out of hospital as she had become accustomed to the life of a patient:

*Mrs B: only thing I found is when you come out, I felt most peculiar, I was in there for 9 days and I don't know whether you become accustomed to having your dinner and your tea made for you and it felt really peculiar to come home and start doing it all for yourself.. I didn't mind doing it but it's just like when you come back off holiday only in a different way and I mean you have been waited on and all that.* ***(62, married female, retired, no previous TKR)***

Three informants also found the first few days at home frustrating as they could do very little, leading to feelings of helplessness:

*Mr O: I was so frustrated, I couldn't drive, I could hardly walk across the floor, it was a chore walking up the stairs.. I used to stand at the back door and I would look at my car at the just felt totally useless to be honest, waited on hand and foot by my family.. I am used to being able to do everything by myself and we play an active role together doing everything, all the housework, looking after four kids, and me having to sit around and people bringing me my food and drink.* ***(40, married male with family, on disability allowance, previous knee operations)***

Support and encouragement from family and friends were an integral part in this period (Mr O, Mrs E, Mr S):

*Mr O: my wife was here and she looked after me and brilliant neighbours, my neighbours would take me to my appointment at the clinic.* ***(40, married male with family, on disability allowance, previous knee operations)***

According to nine of the informants, the success of the recovery depended on how much effort and time they committed to it. Helping oneself in the recovery period was thought to be important in order to obtain the maximum range of movement, to avoid the joint stiffening and to expedite the return to 'normality'. Although the informants believed the recovery was dependent on the individual, most stated that there was a lack of information from the hospital about the recovery process:

> *Mrs L: no not a lot was said about it really, just left to your own devices, oh yes and they get you up as quick as they can.* ***(80, widowed female, retired, previous THR)***

The adage *'no pain, no gain'* was often used to describe the recovery process:

> *Mr O: within the first couple of weeks you have really got to push yourself to go through the pain barrier really.. and make sure you can get the range of movement before everything is healed, and if you don't have the range of movement that you expect to have so then try to get the range of movement afterward it's healed would be a lot more painful.* ***(40, married male with family, on disability allowance, previous knee operations)***

The drawbacks associated with helping oneself in the recovery process included over-exertion (4):

> *Mrs B: when I first came home I must admit I went a bit mad and it knocked me back a bit but I started to be sensible afterwards and it was ok.* ***(62, married female, retired, no previous TKR)***

Mr S felt that having a good education, faith in God, a good GP and a supportive family facilitated his recovery:

> *Mr S: we all have difference education and thoughts.. an uneducated person, it might not affect him because he would know nothing else but on the other hand it might affect him cos he is trying to find out in his head, what's going to happen, so he never accepts it, and therefore he gets a worse outcome than what I would cos I am educated. so other people cope with it differently, but if you have got a good supportive family and a good GP, you have got a belief, I don't mean running to the vicar in the church all the time, a belief within yourself, all these things combined are better than any medicine and if you have got mind over matter, and you have got a belief in yourself even, not just God, if you have got no belief in yourself, you go around with your head in the sand, then you have had it.* ***(64, married male, retired, previous knee operations)***

## Summary

The ten informants described the experience of the processes of the pre-assessment clinic, operation, hospital treatment and recovery. On the whole, the informants were apprehensive before going into the hospital, but once there found the ward atmosphere welcoming. Certain aspects of the treatment were highlighted as problematic. For instance, the prolonged waiting times in the pre-assessment clinic, the organisation of available of beds once admitted, information about the scar, what was expected of them in the hospital, and information about the recovery once discharged, were raised as aspects which could have been improved upon. Positive aspects of the treatment included the hospitable staff, the camaraderie between ward patients and the fact that they had an epidural instead of a general anaesthetic. The informants also had mixed views about the consultant, with some perceiving them as approachable and others as inaccessible. Many of these views were similar to their pre-operation hopes and fears.

The next section describes the outcomes of the TKRs from the informants' points of view.

## Making sense of the TKR outcome

Analysis of the informants' perceptions of the TKR outcome produced some surprising results. Although the majority of the informants stated that their TKR operation was successful, nearly all were still experiencing pain and immobility, six months post operation. Thus, there was much confusion and contradiction amongst the informants' statements, as their overall positive perception of the TKR outcome did not always reflect the pain and immobility they were still experiencing. Table 7.2 presents this information.

As stated above, a major theme to emerge from the post-operation interviews was the informants' declaration that they had achieved a 'good' or 'excellent' outcome. Nine stated that the TKR outcome was either 'excellent' (Mrs J, Mrs B), 'very good' (Miss D, Mr T, Mr S) or 'good' (Mrs L, Mrs M, Mr P, Mr O). The remaining informant (Mrs E) was 'unsure' about her TKR outcome:

> *Mrs B: excellent… the recovery was pretty quick, they get you up and moving about quite quickly. I wasn't sort of as immobile as I expected to be.. I could get about in the house quite quickly without sticks, so yeah, I had an excellent job done.* ***(62, married female, retired, no previous TKR)***

> *Miss D: I have had a very good outcome oh yeah.. I'm happy with the result, yeah very worthwhile doing.* ***(64, single female, retired, no previous TKR)***

However, despite these positive descriptions, almost all (8) of the informants stated they still either experienced continued pain but significantly improved mobility (Mrs B, Mr S), or continued pain and only a relatively small improvement of mobility (Mr P, Mrs M, Mrs L, Mr T, Mr O, Miss D):

> *Mrs B: but… I am getting pain down the back of my leg and I wondered whether.. have I been stupid and done something silly and caused it all. And I sometimes get stiffness, sometimes yes.* ***(62, married female, retired, no previous TKR)***

> *Miss D: I do get a lot of pain sometimes still. I was kneeling on the bed to get myself across to the window and I couldn't, that was very painful with both knees… and it's still not very happy about shopping… I think that's the only thing now and getting up and down stairs but that's a bit more difficult because there is the problem of*

*falling on stairs so I have got to be a bit more circumspect on that.* ***(64, single female, retired, no previous TKR)***

*Mr P: I don't suppose I am more mobile at the moment and I wasn't expecting to have the pain that I am getting on the side because I thought with the joint being gone it was going to be ok.* ***(48, single male, on disability allowance, no previous TKR)***

Mrs J (one of the two stating an 'excellent' outcome) was the only informant to report having a pain free joint and improved mobility:

*Mrs J: I mean the end results are excellent because you are out of that arthritic pain… and you do get your mobility.. I mean I can't speak for anybody else but I mean mine was excellent.* ***(71, married female, retired, previous TKR)***

The remaining informant, Mrs E, was reluctant to judge her outcome (she said she was 'unsure') as she was still in pain and had restricted movement:

*Mrs E: not sure really, like the mobility, I obviously haven't had that properly at the moment but erm it's beginning to come and er.. but like I said I was told that er, I would only get 85% mobility back but then I think it depends on the person, I mean you don't ever know do you, I thought well within 3 or 4 weeks I should be skipping.* ***(64, married female, no previous TKR)***

Thus, when assessing the outcome of the operation, the majority of the informants appeared determined to view their operation as a positive experience, despite still experiencing pain and immobility. The next section explores possible reasons why the informants' accounts appeared to be inconsistent. Thus, to understand the basis of apparent contradictions, the data were examined as case studies first and then reasons for inconsistencies were explored.

*Table 7.2 Patients' statements of TKR outcome and symptoms experienced six months post-operation*

| Informants | Statement of TKR outcome | Symptoms experienced six months post-operation |
|---|---|---|
| Mrs J | **Excellent**<br>*'I mean the end results are excellent I mean I can't speak for anybody else but I mean mine was excellent'* | **Pain free joint, improved mobility**<br>*'because you are out of that arthritic pain… and you do get your mobility'* |
| Mrs B | **Excellent**<br>*'excellent… the recovery was pretty quick, they get you up and moving about quite quickly. I wasn't sort of as immobile as I expected to be.. so yeah, I had an excellent job done'* | **Still experiencing pain, improved mobility**<br>*'I am getting pain down the back of my leg and I wondered whether.. have I been stupid and done something silly and caused it all. And I sometimes get stiffness, sometimes yes'* |
| Miss D | **Very good**<br>*'I have had a very good outcome oh yeah.. I'm happy with the result, yeah very worthwhile doing'* | **Still experiencing pain, restricted mobility**<br>*'I do get a lot of pain sometimes still. I was kneeling on the bed to get myself across to the window and I couldn't, that was very painful with both knees… and it's still not very happy about shopping… I think that's the only thing now and getting up and down stairs but that's a bit more difficult'* |
| Mr T | **Very good**<br>*'it is very good, and getting better, I haven't got no complaints and that's straight up'* | **Still experiencing pain, restricted mobility**<br>*'well.. no… actually… it's just that I expected a bit more out of it, I still can't walk up and down stairs right because I can't get the flexion..'* |
| Mr S | **Very good**<br>*'great.. mine was very good.. all I know is that it was very good for me and yet I didn't think it was going to be'* | **Still experiencing pain, improved mobility**<br>*'a lot of pain, which has gone.. not gone completely but it has eased it up quite a lot'* |
| Mrs L | **Good**<br>*'I think it is good, quite happy with it'* | **Still experiencing pain, restricted mobility**<br>*'as I say I still have got pain… I still can't do a lot yet'* |
| Mrs M | **Good**<br>*'[field notes] Mrs M believed she had a good outcome and was satisfied with the operation.* | **Still experiencing pain, restricted mobility**<br>*'[field notes] Mrs M still finds it difficult to get on and off buses so tends not to use them too much. Mrs M said that the knee was pain free apart from when she does too much* |

*Table 7.2 Patients' statements of TKR outcome and symptoms experienced six months post-operation (cont'd)*

| Informants | Statement of TKR outcome | Symptoms experienced six months post-operation |
|---|---|---|
| Mr P | **Good**<br>*'everything seems to have gone ok.. quite good. the joint now is quite good I have got quite good bend in there now whereas before I could only get about 90 degree bend'* | **Still experiencing pain, restricted mobility**<br>*'I don't suppose I am more mobile at the moment and I wasn't expecting to have the pain that I am getting on the side because I thought with the joint being gone it was going to be ok'* |
| Mr O | **Good**<br>*'it's good.. I say on a scale of 1 to 10, I am probably at the moment at a 8, so I'd say it's good at the moment'* | **Still experiencing pain, restricted mobility**<br>*'but like I say there is still some pain there and I don't have the range of mobility that I hoped to have'* |
| Mrs E | **Unsure**<br>*'not sure really I am a little bit disappointed with the outcome yes, but I mean I know it will come'* | **Still experiencing pain, restricted mobility**<br>*'like the mobility, I obviously haven't had that properly at the moment but erm it's beginning to come, I thought well within 3 or 4 weeks I should be skipping'* |

## Case studies

The case studies described the informants' pre-operation hopes about the TKR, as well as their views on the operation and outcome. They illustrated how important it was to view the informants' statements on the outcome of the operation within the context of their life situations. The case studies were chosen to illustrate the different views stated about the TKR outcome. For example, the first three cases (Mrs L, Mr O, Mr S) were chosen to represent those informants who viewed the TKR outcome as positive yet were still experiencing pain and disability. The fourth case study (Mrs E) described the situation where the view to the TKR outcome was mixed with both disappointment (due to the remaining pain and immobility) and hope for improvement. The fifth case study (Mrs J) was chosen to demonstrate the view of a successful TKR outcome, with pain relief and increased mobility. The remaining five cases conformed to those described above.

### Mrs L

At the pre-operation interview, Mrs L, a 79 year old woman and a widow, was very lonely. Her husband had recently died and she was living in sheltered accommodation, where there was little community spirit. The impact of her OA added to her loneliness as she was restricted to her home and could not participate in her usual activities. Although she knew that it was best not to 'give way to' her OA, she admitted that she had lost all determination and drive in life and was now a 'frightened, nervous old woman':

> *Mrs L: [informant is upset] well I think a lot of my problem is loneliness.. where I used to live, there were plenty of shops and neighbours and people were very friendly.. but here I don't see anybody here for at least a month perhaps and next door I might see them but they are not what I call friendly .. I try not to give way to it.. but I used to be so determined.. I used to be quite an intelligent active person and lately I have got.. I am frightened of everything, that's why I can't understand now that I seem to give up*

There was a chance that she might move into new housing accommodation, where she knew the residents and enjoyed the welcoming atmosphere. She wanted to move there but was unsure about any available vacancies:

> *Mrs L: hopefully now my name is down on this other flat.. yes that would be better and I get on very well down there and they are all*

*lovely, they make you feel wanted but when I come here… excuse me [informant is upset] and I am miserable.. sorry.. it's the loneliness (I: mmm, are you all right) but if you are in company you don't take any notice.. no I go [to visit friends in other housing accommodation] tomorrow and I really look forward to it.. I don't know but they said that I was second on the list.. well there is a flat going but whether I will be lucky, I don't know.. whatever it is I will take it because they are ever so much a friendly lot down there and the flats are lovely.*

Mrs L was apprehensive about the TKR as she had been warned in the past (by her GP) that TKRs were complicated procedures with considerable risks. She was also informed that TKRs are not as successful as THRs. As a result she had delayed her operation:

*Mrs L: well I went to a doctor many years ago and he was saying then, 'oh no, he wouldn't advise a knee operation because he said it's not a success'... but I wish I had had it done years ago, I'll tell you that now..*

However, after more recent discussions with her GP, they agreed that she should have the TKR, due to increasing pain severity and immobility. Mrs L was also encouraged by her family to go ahead with the operation:

*Mrs L: well he [GP] thinks now I ought to have it, he thinks that it's getting worse and it will give me a new lease of life and he says that if they are not sure they wouldn't do it…*

*Mrs L: and like my son says, he's pretty sensible, 'well it's not as if they are going inside mother, it's only the knee'.. you know he seems to think it will be all right... so it's different..*

Thus, Mrs L viewed the TKR as the 'last resort', and said she had to 'put her life in the lap of the Gods'. Although she did have concerns about the effect her co-morbidities could have on her outcome, her pre-operation hopes were to be pain free, and to have improved mobility.

At the post-operation interview, Mrs L viewed the success of her TKR outcome as 'good':

*Mrs L: I think it is good, quite happy with it, I am walking better oh yes I am walking well.. I don't feel so worn out all the time, and more agile*

However, she admitted that she had as much pain as before and her mobility was still quite restricted:

*Mrs L: but the pain.. how I feel now I would say I would never have it again... you see I can't say I am any better, I am still in more pain now than what I had, and I still can't do a lot yet*

Mrs L raised a number of reasons as to why she viewed the outcome of the TKR as 'good', despite this continued pain and restricted mobility. For example, she believed that the healing process was not yet complete, thus more time would be needed for a complete recovery. In addition, Mrs L believed that the healing process might be different for different people, and accepted that she had a slower healing time. She rationalised that because the TKR was such a major operation, it was normal to experience pain and immobility six months post-operation and that TKRs are less successful than THRs (reflecting her GP's opinion). She also compared her outcome with other people she knew who had had a TKR. These people, according to Mrs L, experienced a lot of pain as well, thus Mrs L was reassured that it was not just herself who experienced pain after the TKR. Additionally, she stated that her other knee prevented her from exercising the replaced knee, and this resulted in pain and immobility. She also blamed herself as she had only just started her knee exercises six months post-operation. This was due to feeling unmotivated about doing the exercises and also on the lack of information given about the recovery by the hospital. However, she was grateful for having had the operation that she had waited many years for, and the care she received at the hospital.

A major reason for her positive outlook was the change in her living situation. Immediately after being discharged from the hospital, Mrs L had moved into the new housing accommodation that she had mentioned in the pre-operation interview. As a result, Mrs L felt much better in herself, and this affected her mood and view of the TKR outcome. She explicitly stated that had she still been living in her old house, she would have felt a lot worse off:

*Mrs L: I don't think I would have liked it, I am much better down here, people care about you. if I had been on my own it would have been a lot worse, definitely.. I am much happier.. I feel that each morning now that it should be feeling better.. cos I like it down here, very nice. I was very down the last time I saw you but I am a lot better because they are all very friendly here, we are not in one another's houses but they are good, like today my friend went up and she got me a nice piece of fish, at the fish shop and then she will come in to say 'are you all right', things like that like.. it's very nice without being too much... it's a different atmosphere here.. how people are makes a lot of difference.*

In summary, Mrs L was very anxious about the TKR at the pre-operation interview, due to the negative views portrayed to her about the operation. She also found her housing situation depressing and isolating, which added to her worries. At the post-operation interview, she stated that she had a good outcome but admitted to being in as much pain as before the operation. Her recovery process coincided with her move to a new residential home, and this positively affected her view of her TKR outcome.

## Mr O

Mr O, a 40 year old married man, with a young family of four, was on disability allowance when interviewed three months before his operation. Mr O stated that he was frustrated as his OA had affected all aspects of his life: his occupation, his sporting activities and his parental/marital role in his family. Mr O was aware that he was relatively young to undergo a TKR, but viewed the operation as the 'last resort'. Mr O had seen two consultants before being listed for surgery. The first consultant admitted that he was unable to make a diagnosis of his knee condition and referred Mr O to another consultant:

> *Mr O: and he [1st consultant] said to me 'I've looked at your knee' and he said, 'I have no idea at all what's going on in there', he can see that something terrible is going on inside the knee but he had not got a clue and he said 'I don't know what else to do, so what I'm going to do is refer you to somebody who I think maybe be able to help you, if he can't help you then I don't know anybody else who can' and I was then referred to Mr 1.*

The second consultant was able to make a definite diagnosis and stated that Mr O had a condition called 'synovial chondromatosis', which had complicated and exacerbated his knee OA. However, rather than perform a TKR, the consultant offered to fuse the knee, so it would be pain free but stiff. In another 20 years time, the consultant said he would then unfreeze the knee and perform a TKR, so Mr O could have the quality of life when he was older. Mr O refused this and said he wanted the quality of life now and then have the leg fused when he was older. Nevertheless, the consultant insisted on performing two other operations before the TKR, to see if they improved the joint. Although it did relieve a lot of the pain, Mr O was still restricted, so the consultant finally decided to go ahead with the TKR:

> *Mr O: he [2nd consultant] then told me I had some rare condition called "synovial chondromatosis" which is what has actually helped to exacerbate things and complicate things in the knee... Mr 1 didn't offer*

*me a knee replacement, he offered me the straightening of the leg which I said no chance to... I was horrified to have like a stiff leg, I was horrified and I said 'you must be joking', I said I would rather put up with the pain for the rest of my life that I was experiencing rather than have that done to my knee.*

As a result Mr O had convinced himself that the TKR was the 'holy grail' and believed it would relieve all his pain and immobility. He hoped for complete mobility and pain/stiffness relief, to have more independence, to walk without crutches/limp, and to be able to do things normally. In addition, drawing on the experience of his next door neighbour (who had had a TKR ten years ago and is now a fitness instructor) he hoped to be able to return to sports and his occupation.

At the post-operation interview, Mr O regarded his TKR outcome as 'good':

*Mr O: it's good... I say on a scale of 1 to 10, I am probably at the moment at a 8, so I'd say it's good at the moment..*

However, Mr O was still experiencing pain and restricted movement:

*Mr O: but like I say there is still some pain there and I don't have the range of mobility that I hoped to have.*

Mr O gave several reasons why his outcome had not completely been fulfilled. He stated that that the recovery process was not fully complete, and also that the knee had been under a lot of trauma before the operation. He also believed that he had done too much too soon, and therefore injured the knee before it was properly healed. In addition, he underplayed and dismissed the remaining pain, and accepted the fact that he was going to be a life-long tablet taker and that he would always be 'slightly disabled' for the rest of his life. He also compared his outcome with other people who had had a worse outcome than himself, and believed that he had coped well throughout the recovery process. Although Mr O was appreciative that he had had the TKR operation, he admitted that his hopes had been too high at the pre-operation interview:

*Mr O: Like I said I am not as quick as I expected or thought I would be able to do but it's getting there, I mean everybody says to me I am expecting too much too soon.*

As a result of this, Mr O stated he had to modify his views, and was resigned to the fact that his ideal outcome was not completely fulfilled:

*Mr O: I have had to modify my thoughts on everything to be quite honest.. yeah.. I used to play a lot of badminton and it's really to restrict*

*myself from doing anything like that and just use the leg really for walking around and getting from A to B.. so at the end of the day it's just one of those things you have just got to put up with.. welcome to the real world and just not be able to carry on doing the things that I enjoyed doing*

This resignation was also due to the fact that the consultant had told Mr O that the 'synovial chondromatosis' may have affected his recovery and outcome. Thus, having a medical reason for his continued pain and immobility appeared to help Mr O accept it and was happy to be monitored more closely than normal:

*Mr O: I seen the consultant who did the op a few weeks ago and he doesn't understand why I have still got that pain, er.. but I am being monitored apparently more than normal anyway simply because of the condition that I had in the knee as well.. synovial chondromatosis.. which they hoped to have got rid of now.. in fact when I went there the last few weeks he took some x-rays and he talked about this shadow that he could see which he wasn't quite sure what it was, wasn't sure if it was the old problem coming back again because if that comes back it's going to bugger up this new joint so he wasn't absolutely sure what it was, erm, he didn't say to me that it was the synovial chondromatosis that was back but he intended to monitor it a lot closer just to make sure things are moving ok.. so he will just send me an appointment as he thinks it's necessary but he certainly hasn't discharged me from his care*

Furthermore, Mr O, being a young man knew that revision operations were inevitable. He was aware of the difficulties involved in revision operations and was thus determined to view the TKR outcome positively and to make the prosthesis last as long as possible:

*Mr O: I mean he said to me that he was pretty confident that he will probably will have to do a second replacement and how well that goes really depends what's there cos each time they go in obviously they got to take a bit away to actually get the thing to fit.. so it's possible I might be able to have a second, it's unlikely I will be able to have a third.. very rarely they will fit a third but I am hoping I can make this one last as long as possible and if I have to have a second to make that last the rest of my life*

He was also determined to portray to his family that he had made the right decision to undergo the operation:

*Mr O: hopefully with a lot of help from my other half and the kids because I was always moaning and sometimes I would be crying or whatever.. if I went upstairs and fell down.. if I was walking out into the kitchen, the next minute I would be on my bum. I want to prove to*

*them that I can do it, cos these last few years have been hell for them too.*

In summary, Mr O had very high hopes of the success of the TKR operation. He was determined to regain his mobility and relieve the pain of the OA and return to normal activities. Having a young family and the desire to return to work compelled him to view the TKR with high regard. At the post-operation interview, despite the fact that his hopes had not been met to the full extent, Mr O regarded his outcome as good. His determination to improve his family life, and the knowledge of future revision operations encouraged Mr O to view his TKR outcome in a positive way.

**Mr S**

Mr S, a 64 year old male, was an ex ship-yard worker, and currently on disability allowance. He found being at home both depressing and lonely:

*Mr S: I don't like being home to tell you the truth, it's better to be out cos you can enjoy it and appreciate it when you are home. I have been on my own all the time, I have been on my own until my wife retired.. I have sat in this room all the winter.. the worse thing that hit me was when my doctor told me that I would never work again, I would have to go on invalidity allowance, when not going to work again, it's not the fact of going to work... but you have got a comradeship that you would not get anywhere else so when all that is finished and you are not going to work, you ain't got your mates, what we called the crack, that's having a joke and a laugh*

Mr S appeared to be very bitter towards the NHS, as he believed he had received poor care and 'crude surgery' on previous hospital visits. In addition, he believed that the surgeons had delayed his surgery for reasons not disclosed to him. As a result of this delayed surgery, he thought that his knee was damaged beyond repair. Mr S was also a staunch Christian and believed that tampering with the human body was sacrilegious. For these reasons, Mr S had very negative views on the potential success of the TKR:

*Mr S: I don't get no hope. I am not very hopeful, sometimes I wonder what is going on, have I been messed about, but I got the impression that they were delaying.. there is a delay for some reason .. I don't think personally it is going to be all that successful, that's my opinion cos I don't think it can be and I think there must be a position with that knee or something wrong or they know but they don't tell me*

However, at the post-operation interview, Mr S viewed his outcome as 'very good':

*Mr S: great.. mine was very good.. all I know is that it was very good for me and yet I didn't think it was going to be*

This was stated despite still experiencing some pain and immobility:

*Mr S: a lot of pain, which has gone.. not gone completely but it has eased it up quite a lot and I have got to watch it cos I still lose my balance pretty quick.. I have got to go very careful still*

However, Mr S believed he had coped well in the recovery process and viewed his outcome as positive, especially when compared to other people's outcome. He believed that people have different healing times and thought he had healed quickly from the operation. The remaining pain that Mr S experienced was attributed to the impact of his sciatica. It was apparent from the post-operation interview that the outcome of the TKR proved better than Mr S had anticipated:

*Mr S: yes it's much better than I expected, I wasn't expecting miracles so it has proved a lot better than I was actually anticipating*

At the post-operation interview, Mr S admitted he was very pessimistic before the operation, as he believed it was better to be pessimistic and hope for nothing, than to have high hopes. Mr S said that if he had gone into hospital with high expectations he would be worse off because he would have been disappointed if he had not achieved the expected result:

*Mr S: you have got to be very pessimistic, that's how I was when you came the last time.. I was very pessimistic.. if I had had great expectations, if I did, I would had been worse off.. by going in with an pessimistic mind, that's how it had to be taken, I realise that, I am not stupid, I know for a fact.. that's how I take life, I don't expect anything, I don't give myself, I don't ask for anything, I never have.. if people go in thinking they are getting more than what they are going to get, and they jump out of bed and walk to the toilet, they will be disappointed.. it takes time and a lot of patience*

These views reflected Mr S's religious beliefs. As a result of his improved outcome, Mr S believed that this experience was God-made. He stated that God had made him go through the operation in order to make him a better man. He felt that God had made him have OA and the TKR for a purpose: it was *'Gods way'* of showing him how to be a better person:

*Mr S: I don't think you should go and expect anything, you should have what's given to you.. I don't want to keep on all the time but that's*

*training by God, he trains people, my doctor is a Christian and most doctors are, we all are*

*Mr S: I accepted it afterwards, as I realised it was Gods way in any case, that was something to do with him in the first place, so bringing the two together and by weighing them up, I accepted it.. but I believe it was for a reason, I don't know what the reason is, whether it is to make me better or to show others, or to talk to you, or to communicate or to bring me down to earth, maybe I was getting out of hand, not realising it*

In summary, Mr S was very pessimistic about the success of the TKR at the pre-operation interview. It was only at the post-operation interview that he explained reasons for this pessimism: to avoid disappointment with the outcome and to be faithful to his religious beliefs. Mr S's outcome proved better than anticipated, although he still experienced some pain and immobility. He rationalised his experiences in terms of his religious beliefs.

**Mrs E**

Mrs E, a 64 year old woman, lived with her husband and was a retired industrial cleaner. At the pre-operation interview, Mrs E described herself as coming from the 'old school', and believed that young GP's/doctors were not interested in 'old people's problems'. Due to her OA, Mrs E found most activities very difficult and would be housebound without the help of her husband. Her life had changed dramatically, and she even found walking short distances unbearable. Her knee pain was constant (even when resting) and excruciating, and she felt suicidal at times.

Mrs E was very apprehensive about going into the hospital. Although she dearly wanted to have the operation and hoped that it would relieve her pain and immobility, she feared going into the hospital, due to negative media stories. For example, she had heard incidents about medical misconduct such as, 'do not resuscitate' on notes, bed shortages, wrong diagnoses, unqualified reception staff taking blood and male nurses poisoning patients. She talked about the TKR as 'pot luck', or 'putting her life in the lap of the Gods'. She offered up two possible outcomes in 12 months' time, describing what she would be like if she went ahead with the operation and what she would be like if she postponed it:

*Mrs E: well if I haven't had the operation I can see myself becoming more of a cripple I think, but if I have it, I hope I get a better way of life, you know, not having to worry about things so much and be more*

*mobile, be able to walk round the shops properly, so quality of life, just plodding along, enjoying life as a whole, that's all, asking no one for anything... but then I think of all the things I have had and I think 'oh no, DNR, DNR*

At the post-operation interview, Mrs E was reluctant to judge the outcome, as she was still experiencing some pain and immobility, and was 'disappointed' with some aspects of the outcome:

*Mrs E: not sure really, I am a little bit disappointed with the outcome, yes, a little bit, like the mobility, I obviously haven't had that properly at the moment, I thought well within 3 or 4 weeks I should be skipping.*

Mrs E tried to make sense of her outcome by stating factors that may have impeded her recovery. She stated that she had no one with whom to compare her symptoms, and therefore did not know what to expect in the recovery process. She also blamed herself for being naive before the operation. This was because she refused to listen to any information given at the hospital, as she was so frightened about the operation. The belief that people have different healing times was also mentioned, as well as believing that it was still in early stages of recovery. She believed that her back pain and other knee affected her TKR outcome and recovery, as well as feeling despondent and low. However, despite these attempts to explain her outcome, Mrs E remained unsure about her outcome:

*Mrs E: at the moment like I said it has taken me to now to sort of come to terms with it all, cos I found it quite traumatic, I got very depressed with it, well I am just beginning to come out of the doldrums with it really and I am six months on*

Nevertheless, Mrs E was optimistic about the future and believed that the recovery process was not yet complete. She hoped for continued improvement of the TKR outcome:

*Mrs E: come back in 6 months time and I will tell you definitely, at the moment, it's ok, like I say I am beginning to get there but I am still restricted but you know, another six months down the line, perhaps I will be doing a tap dance round the room and feel a lot better.. don't get me wrong I am grateful for the attention I got.*

Mrs E, in general, tended to dwell on the negative aspects of her outcome. She became very depressed with her life during the recovery process, and believed that this may have affected her outcome:

> *Mrs E: I had terrible depression, oh gosh, yes.. terrible, of course being a diabetic didn't help much either, you are restricted to what you can have, 'couldn't have that'.. it was the pain first of all I was depressed about. I am a bit of a worrier, and that probably hasn't helped my recovery, my worrying.*

In addition, Mrs E was already worrying about the likelihood of having future revision operations, and the possible complications of having bilateral operations when she was older:

> *Mrs E: cos I mean I am worrying about it being replaced x number of years on, my husband says 'don't worry about that, get on with today, and progress today, just get yourself right now', never mind, x number of years cos I think to myself I have been through all that at this age, what I am going to be like ten or 15 years on and got to go through it all again.. but you can't help thinking about it, cos I think 'god, it was so painful', and I think to myself, 'god a few years on like, if I am spared, I got to go through all that pain, you know again'.* ***(64, married female, no previous TKR)***

In summary, Mrs E was keen to have the TKR operation but was apprehensive about the hospital care in the NHS. At the post-operation interview, she was reluctant to judge the outcome as she was disappointed with the remaining pain and immobility, but was hopeful that in time she would benefit from the operation.

**Mrs J**

Mrs J, a 71 year old married woman, was a retired nurse. At the pre-operation interview, Mrs J said she had had a successful TKR six years ago and hoped that the present operation would be as successful. Mrs J was very positive about life and believed it important to keep the body and mind active: she coped as well as she could and pushed herself to do things. She believed that being positive would help her in the recovery:

> *Mrs J: I mean if you take a positive attitude I suppose things can turn out a lot better, so you've got to have a positive attitude to life, that's what you got to have... and you haven't got to grumble, no good to grumble, you mustn't grumble, you just take things as they come and cope with things as the come.*

Mrs J hoped for pain relief, increased mobility and independence. She wanted to have an improved quality of life, have no worries about the knee, stop her painkillers, and limit her visits to her GP.

At the post-operation interview, Mrs J viewed her TKR outcome as 'excellent':

> *Mrs J: I mean the end results are excellent because you are out of that arthritic pain… and you do get your mobility.. I mean I can't speak for anybody else but I mean mine was excellent.. things are more of less back to normal.. very pleased.. over the moon*

She was the only informant to report having both a pain free joint and improved mobility:

> *Mrs J: I mean you can cope and carry on and walk without pain.. that is the biggest joy, you know, you are out of pain and it's mobile so no problem… and I'm independent, it's what you need is your independence, I mean I have been independent from day one when I came home because I walk about and do things, I mean it doesn't stop me doing anything*

Mrs J expressed the importance of helping oneself to ensure a successful recovery. She thought her positive attitude helped her through the operation and aided her recovery and outcome:

> *Mrs J: so it's your positive attitude, yes I still think that, I mean it is, I mean a lot of people can't stick pain but it's something that you have got to stick at for a while, you have got to, and I mean the end results are brilliant because you are out of that arthritic pain*

She also believed that her good healing skin aided her outcome and recovery. However, despite Mrs J's outcome being successful, in terms of the pain relief and increased mobility, she stated that the recovery was a lot longer than her previous TKR. She attributed this to her pre-operation view that second operations are more problematic:

> *Mrs J: well they do say that the second one is not so good as the first which I found in the first place, you know I wasn't getting over it so quick but it comes, it just comes.* ***(71, married female, retired, previous TKR)***

In summary, Mrs J was very positive about the TKR outcome, both pre- and post-operation. Her main hopes had been met, as had a pain free joint and better mobility. She therefore viewed the TKR as a miracle. She believed that having the right attitude helped her recovery and outcome.

## Summary of case studies

The informants raised several major factors when they explained their outcome, and this illustrated the struggle they experienced in their attempt to make sense of their outcome. It was necessary to examine the data as case studies first as it was important take into account their life context and experiences, hopes and fears regarding the operation. When each case-study was examined, their views made at the post-operation interview made sense in the context of the pre-operation data.

## Thematic data: rationalisations of outcome

Although each case was essentially unique, there were a number of cross-cutting themes that were similar between the informants when assessing their outcome. The next section documents these commonalities, which are be divided into four sections: the method of questioning satisfaction, the reasons behind the desire to report a successful outcome, the factors believed to have affected their outcome and self-blame. This information is summarised in Table 7.3.

## Method of questioning

One of the factors influencing the immediate positive statements about TKR outcome was the method of questioning. The positive evaluations tended to be stated on direct global questioning about their outcome. Questions such as "How satisfied are you with your knee replacement outcome?" often resulted in what appeared to be a socially and personally desired response. For example, the following quotations represent the standard reply from the informants when asked the above question:

> *Mr T: it is very good, and getting better, I haven't got no complaints and that's straight up.* ***(66, divorced male, retired, previous operations)***

> *Mrs B: excellent… it's worked.. I can do things much quicker now.* ***(62, married female, retired, no previous TKR)***

It was only on further questioning about the outcome that many of the informants (Mr T, Mrs B, Mrs M, Mr O, Mr P, Mrs L, Miss D, Mr S) admitted to the limitations of the TKR outcome:

> *I: so can you do everything that you want to do then?*

*Mr T: well.. no… actually… it's just that I expected a bit more out of it, I still can't walk up and down stairs right because I can't get the flexion..* ***(66, divorced male, retired, previous operations)***

*I: so does it limit you at all now?*

*Mrs B: well I can manage to walk upstairs properly now, you know but I still come down backwards.. it's still a lot more awkward walking down than it is up.. and I still sometimes get stiff.. if I have been doing too much.* ***(62, married female, retired, no previous TKR)***

**Desire to report a successful outcome**

This reaction of reporting a successful outcome despite continued experience of pain and immobility may reveal the very human desire to believe they had made the right decision in having undergone the operation. For example, Mrs L, who admitted to being in as much pain as before the TKR, was grateful for the operation, believing that the 'bad' OA had been removed. She stated that the knee was 'bound to be better' and therefore regarded her outcome as good:

> *Mrs L: you see I can't say I am any better, I am still in more pain now than what I had, oooh I mustn't say that because I have, cos I am bound to be better (I: why?) well I mean they have taken the bad out and they were very good in hospital, no I think it is quite good.* ***(80, widowed female, retired, previous THR)***

It may also reflect the informant's gratitude for having had the operation and the care given in the hospital, for which they had waited many years (Mr O, Mr P, Mrs L, Mrs M, Mrs J, Mrs B):

> *Mr O: I am still restricted but you know, don't get me wrong I am grateful for the attention I got, they looked after us and saw that things were done properly… and this [TKR] was the last resort .. so all in all, it was pretty good.* ***(40, married male with family, on disability allowance, previous knee operations)***

> *Mr P: well I would say good on everything as far as the hospital, staff, operation.. but I am still getting.. if I sit in the chair with my legs up like that [straight] and I try to get off, it is really painful then, so I don't know why that is, like I say it can't be the actual joint or the operation, there shouldn't be anything there now so.. no they were very good to me in the hospital.* ***(48, single male, on disability allowance, no previous TKR)***

In addition, the majority of informants (Mr O, Miss D, Mrs L, Mrs J, Mrs B, Mr P, Mr T, Mr S, Mrs M) reported that they had coped better than expected with the TKR operation, and this may be a reason for a positively reported outcome. For instance, four informants actually stated that their TKR was not as terrifying as they expected, and thus felt positive about the TKR outcome:

> *Mrs M: it's good… cos I thought it was going to be worse than it actually was... it's not too bad after all.. I don't think it was as bad as I thought it would be, so yes I am pleased with the result.* ***(81, widowed female, retired, previous TKR)***

Another reason for the perceived positive TKR outcome was the fact that the TKR was indeed beneficial in some aspects of the informant's life. For example, movement, pain, or both, were improved, to varying degrees, and for some this made a significant difference to their life. For these informants, the remaining pain was mild enough for them to be able to live and cope with it, and therefore they perceived the TKR outcome as being a success:

> *Mr P: it has made a difference even just doing normal things you know, so it's been good.. ok, I am still not pain free but I got enough back to cope and carry on.. that is the biggest joy, you know you can do certain things again.. it has made a difference.* ***(48, single male, on disability allowance, no previous TKR)***

Comparisons were also made to their physical state before the operation and the problems they would have experienced had they not had the operation (Miss D, Mrs L, Mrs E, Mr S):

> *Miss D: before the op, it just got steadily worse, by the time I went in I could.. well I could walk but it was an extremely painful and difficult.. it was just as well that they got to me when they did because I would have been practically immobile if it had gone on much longer… so it's much better compared to then.* ***(64, single, female, retired, no previous TKR)***

*Table 7.3 Making sense of TKR outcome*

| | Statement of TKR outcome | Symptoms experienced six month post operation | Perceptions of TKR outcome |
|---|---|---|---|
| Mrs J | Excellent | Pain free joint, improved mobility | Expected excellent outcome like previous TKR. Different healing times. Delayed recovery due to second operations being more complicated. |
| Mrs B | Excellent | Still experiencing pain, improved mobility | Did not have high pre-operation expectations. Belief that TKRs not as successful as THRs. Self-blame. Lack of information. |
| Miss D | Very good | Still experiencing pain, restricted mobility | Did not have high pre-operation expectations. Flu. Other knee. Lack of information. |
| Mr T | Very good | Still experiencing pain, restricted mobility | Recovery process not complete. Age. Other knee. Information misunderstood. Self-blame. Different healing times. |
| Mr S | Very good | Still experiencing pain, improved mobility | Did not have high pre-operation expectations. Sciatica. |
| Mrs L | Good | Still experiencing pain, restricted mobility | Recovery process not complete. Major operation. Lack of information. Different healing times. Belief that TKRs not as successful as THRs. Other knee. Self-blame. |
| Mrs M | Good | Still experiencing pain, improved mobility | Recovery process not complete. Major operation. Age. Lack of information. Different healing times. |
| Mr P | Good | Still experiencing pain, restricted mobility | Recovery process not complete. Major operation. Age. Overweight. History of weak knee. Depression. Other knee. Lack of information. Self-blame. |
| Mr O | Good | Still experiencing pain, restricted mobility | Recovery process not complete. Trauma. Self-blame. |
| Mrs E | Unsure | Still experiencing pain, restricted mobility | Recovery process not complete. Depression. Other knee. Back pain. Belief that TKRs not as successful as THRs. Avoided information. Self-blame. Different healing times. |

In addition, comparisons of outcome were made with other people's TKR outcome (Mrs L, Mrs E, Mr T, Mr O, Mrs M, Mr S). For example, the TKR outcome was viewed as positive when compared to other people worse off than themselves (Mr T, Mr O):

*Mr O: you know the number of people on the ward who are crying and moaning because there is so much pain around and some of the things I have seen, I think to myself I am lucky really, it's just a knee replacement, I have seen people with amputations and so on and so forth.. there are people walking in the same day as me on both their legs.. there was one woman came in at the same time as me on both her legs and when she was going home she had one of them cut off.. I couldn't believe it so I got away pretty lucky, it was good.* ***(40, married male with family, on disability allowance, previous knee operations)***

The one informant who was unsure about the outcome was Mrs E. She was reluctant to judge her outcome as she was disappointed with the remaining pain and immobility, but was aware that it had also done her some good:

> *Mrs E: I'm unsure really, I wouldn't want to say .. a little bit disappointed, but I am getting there very slowly, well yeah because erm, you know I still can't go round the shops and walk to ..but I think it has also done me some good put it that way, and I think it will eventually, it's just having the patience to see that two year gap out, so and I mean you have got to give it a chance.* ***(64, married female, no previous TKR)***

## Delayed recovery/outcome

The informants cited a number of factors that they believed had an impact on their recovery and outcome. More than half (Mrs M, Mrs L, Mrs E, Mr O, Mr T, Mr P) believed the recovery process was not complete six months after the operation, and therefore they could not give a final verdict on their TKR outcome. They believed that they still experienced pain and lack of mobility because they needed more time to improve:

> *Mrs L: I mean I have got to give it another 2 or 3 months anyway, you know I thought when I had it done I would be running and walking around but I am not, I still can't do a lot yet so it's got to take time hasn't it... 6 months time I will probably tell you different.. but really I expected to be running around but it doesn't work like that.* ***(80, widowed female, retired, previous THR)***

On a similar issue, three informants (Mrs L, Mr P, Mrs M) acknowledged that because the TKR involved such major surgery, it was only natural to experience some pain:

> *Mrs L: if you have had a big op, he said it was major, you have got to have a certain amount of pain, so that's just normal.* ***(80, widowed female, retired, previous THR)***

Furthermore, six informants (Mrs E, Mrs J, Mrs L, Mr T, Mrs M, Mr S) believed that the healing process was different for different people. Mrs J, who stated she had an 'excellent' outcome and had a pain free joint and improved mobility believed that her *'good healing skin'* facilitated her recovery and outcome. On the other hand, four informants, who were still experiencing pain and immobility, accepted that they might have slower healing times. Therefore they might have to wait for their outcome to improve:

*Mrs E: it just depends on the individuals, well my husband said different people heal differently, don't they, that's the thing, I suppose it just takes time* ***(64, married female, no previous TKR)***

The different healing times were also thought to be dependent on the informant's age. Five informants (Mrs M, Mrs L, Mr P, Mr T, Mrs B) accepted their remaining pain and immobility because of their old age:

*Mr T: but it's when I try to bend it, but I am nearly 67, all of a sudden I looked at myself and I thought 'I am not a young man anymore', I think I have got to be thankful for small mercies, I got to accept the way I am, and hope that in the next year that this will sort itself out and give me a little bit more flexion.* ***(66, divorced male, retired, previous operations)***

*Mrs L: oh yes I am walking well.. I am not saying it doesn't ache of course, when I went to town, when I got back I was glad to get back cos it is really early days for that I think.. so I am doing what I can .. well I will be 80 next month so time goes doesn't it.* ***(80, widowed female, retired, previous THR)***

Other reasons which were thought to have affected their recovery and outcome included having the flu (Miss D), being over-weight (Mr P), the fact that the knee had always been weak (Mr P), feeling depressed or worried about the knee and therefore not exercising it (Mrs E, Mr P), or that the knee had been under a lot of trauma leading up to the operation (Mr O):

*Mr O: I am not as quick as I expected or thought I would be able to do but it's getting there… but the leg has been through a awful lot of trauma over the past couple of years so it's bound to take a little bit more time.. that's okay.. it's getting there.* ***(40, married male with family, on disability allowance, previous knee operations)***

In addition, other informants discussed the impact of other health problems, such as sciatica (Mr S), back pain (Mrs E) or their other knee (Miss D, Mr T, Mr P, Mrs L, Mrs E), which they believed affected their outcome. For example, Miss D thought her TKR outcome had not reached the full benefit because of her other arthritic knee which was causing her problems:

*Miss D: I was looking forward to having perhaps a few months when I was going to be able to cope.. but I suppose it was about the end of November when it [other knee] started letting me know that it was his turn now.. I am just careful about how far I am going to walk in case it's aching a bit, so I can't exercise this knee [replaced knee] as much as I want to.* ***(64, single, female, retired, no previous TKR)***

Lay beliefs, such as 'TKRs being less successful than THRs', were raised by three informants (Mrs B, Mrs E, Mrs L) in an attempt to make sense of their outcome:

> *Mrs E: well they say that the hip is a bad one but apparently the knee is the worse because you are putting all your weight on that joint, you know, so like I said I didn't realise the weight of it.. 8 pounds.* ***(64, married female, no previous TKR)***

More than half of the informants (Mr O, Mr P, Miss D, Mrs B, Mr T, Mrs L) tended to dismiss or underplay the remaining pain and immobility they still experienced:

> *Mr O: it's a couple of areas like I said that there is a niggling little pain and apparently it shouldn't be there but it's no where near as bad as what it was.. it's nothing to write home about.* ***(40, married male with family, on disability allowance, previous knee operations)***

> *Mr T: so the joint is pain free apart from first thing in the morning I got to take a pain killer because all around the joint, it's all uncomfortable and achy, it's not the terrible pain like I had there before, I put it down and I try to get comfortable, so it's not so bad, I just carry on like I always have done and I am sure it will get easier.* ***(66, divorced male, retired, previous operations)***

The remaining pain was considered to be controllable with medication without causing too much disruption to their life:

> *Mr P: like I said even though I am experiencing some discomfort still I can live with it and can keep it under control.* ***(48, single male, on disability allowance, no previous TKR)***

Furthermore, eight of the informants accepted their outcome and conceded that they had to make the best out of what they have got (Mrs L, Mr T, Mr O, Mrs M, Mr P, Mrs B, Miss D, Mr S):

> *Mrs L: I accept that I have pain now, I think it has got to get better, I mean if you think, there's two parts in there, it's bound to be tender and it's got to heal up, and it takes longer to heal inside than out.* ***(80, widowed female, retired, previous THR)***

> *Mr O: I'd hoped to because I was told that the knee would be pain free and I would have 89–90 percent mobility in that leg and I pushed myself but like I say there is still some pain there and I don't have the range of mobility that I hoped to have but I can cope with what I have got now so, it's really making the best out of what I have got.* ***(40, married male with family, on disability allowance, previous knee operations)***

Acknowledging the fact that the recovery had not been fully completed, six of the informants (Mr S, Mr O, Mrs E, Mrs L, Mr P, Mr T) were still optimistic that their outcome would reach its full benefit given time. It appeared that the informants shifted the time line for recovery from six months to 12 months:

> *Mrs E: come back in 6 months time and I will tell you definitely, at the moment, it's ok, like I say I am beginning to get there but I am still restricted but you know, another six months down the line, perhaps I will be doing a tap dance round the room and feel a lot better.* ***(64, married female, no previous TKR)***

> *Mr O: I say on a scale of 1 to 10, I am probably at the moment at a 8 and I am hoping to be at a 9 within the next year.. it's definitely getting better all the time.. my hopes are.. still are.. that eventually I will have 85-90 percent movement in the knee and obviously get rid of the majority of the pain.* ***(40, married male with family, on disability allowance, previous knee operations)***

## Self-blame

A major factor in how the informants made sense of their outcome was related to self-blame; it was the informant's own 'fault' if they still experienced pain and immobility. For example, most of the informants (Mr P, Mrs L, Mr T, Mrs E, Mrs B, Mrs M, Mr O) believed that as the knee joint had been replaced by something new, any problems experienced must be their own fault. It is important to note that the informants never criticised the surgeon or the surgery for their outcome:

> *Mr P: it's nothing to do with the joint now it's more down to me, like I say it can't be the actual joint, there shouldn't be anything there now so.. I think I might of done too much too soon.* ***(48, single male, on disability allowance, no previous TKR)***

> *Mr T: that [OA] has gone, it has cured the arthritis, what they have done is stuck a lump of metal and you stand on that actual joint and there is nothing because it's a lump of metal, but I don't see how they put all the tendons back on to the lump of metal to make it bend, I think it's amazing that they put tendons to make you go like that [bends knee]* ***(66, divorced male, retired, previous operations)***

> *Mr O: I knew what I had to do .. I knew what I had to put myself through.. within the first couple of weeks you have really got to push yourself to go through the pain barrier really.. and make sure you can get the range of movement before everything is healed.. if you don't have the range of movement that you expect to have and then try to get the range of movement afterward it's healed, it would be a lot more painful.*

***(40, married male with family, on disability allowance, previous knee operations)***

Thus, six informants (Mrs B, Mrs L, Mr P, Mrs E, Mr O, Mr T) tended to blame themselves for the remaining pain and immobility, as they believed they were 'over-doing' certain activities too soon after the operation:

*Mrs B: I was getting pain down the back of my leg and I wondered whether.. I mean you hear a lot of people say 'you won't get any pain at all afterwards' and I thought is there something wrong.. have I been stupid and done something silly, I didn't know whether I had done some damage.. cos I did go mad when I came home.. my husband went out on the Saturday, and I was just pottering around just doing different things and really I should have rested it.* ***(62, married female, retired, no previous TKR)***

*Mr P: it was just before Christmas I met up with a few of my old mates who I used to work with years ago, we went down the centre and had a few drinks and I was sat down most of the time there anyway and then we walked from the centre up the hill to a restaurant and I was in quite a bit of discomfort after that, for quite a while, a few weeks after that so I think I might have done too much too soon..* ***(48, single male, on disability allowance, no previous TKR)***

Mrs L believed she was still experiencing pain in her knee because she was using it more. Mrs L had only just started to exercise the knee at six months post-operation. Consequently, once she attempted to exercise the knee, she experienced pain:

*Mrs L: I hadn't been doing a lot until three weeks ago because it was painful, but it's only this last three weeks that I have had this pain because as I say, the only thing I can think is I am using it more.. it can't be the actual joint now because it's not there.* ***(80, widowed female, retired, previous THR)***

A number of issues regarding the information provided by the hospital were given as explanations for the remaining pain and immobility experienced by the informants. Five (Mrs B, Miss D, Mrs L, Mrs M, Mr P) believed that the lack of information had not prepared them for the possible pain and restricted mobility experienced in the recovery process:

*Mrs B: they didn't tell me any of that at the hospital, you had to bend your knee to 90 degrees before they would let you come home but they didn't really tell you.. well I don't suppose you know unless you have actually had the operation.. what it's going to be like.. so it was quite interesting to talk to somebody who had had it done.. my friend, she told me that you could get a bit of pain occasionally but that was*

*more muscle spasms I would imagine than anything else. If you haven't been using it properly and she told me how long it took her to.. but it was interesting to know how somebody had coped with it.* ***(62, married female, retired, no previous TKR)***

*Mrs L: no information, no, not a lot was said about it really, just left to your own devices, they didn't tell me what to do to be honest, and as I said I hadn't been doing a lot until three weeks ago because it was painful.. I mean I just walked about and in the room and out but I am doing a lot more now, I didn't feel up to it.* ***(80, widowed female, retired, previous THR)***

In addition, Mrs E stated her disappointing outcome was because she had avoided any knowledge of any medical information about the process of TKR and its outcome. This was because she was frightened about the actual operation and the possibility of complications:

*Mrs E: I wasn't told how long the recovery time would be, but then again I didn't ask, and er, before I had my operation, there were people in the ward that had had theirs done and the physio came round and they were asking questions, you know, 'what was this, 'what was that', and all this business, I chose to read the paper cos I thought the least I know, I am facing it tomorrow, I don't want to know… I was quite naive and I thought the least I knew the better really, I didn't want to know too much, so I didn't go into it.* ***(64, married female, no previous TKR)***

Thus, as a result of avoiding the information given, Mrs E became so impatient with the slow recovery process that she forced her knee to do activities too soon after the operation. Also, she stated that she did not know of anyone else in a similar position to compare her symptoms with. Mrs E had only heard second hand stories about TKR successes, (e.g. 'some people are running around like two-year olds'), and as a consequence forced her knee to bend before it was ready:

*Mrs E: I have heard so much about different people, like I told you before I have had no one in the family that I can compare with, like I said I have heard different people and they have said 'oh so and so is like a two year old since they have had their hip or their knee', course I have been forcing myself to go upstairs since 4 weeks on, and that was when I got told off because they said the stairs is the last thing really I should accomplish and er that was when I was told more or less that I am too impatient.* ***(64, married female, no previous TKR)***

Another informant also forced his knee in the recovery process. As a result of reading the information booklet provided by the hospital, Mr T compared his own recovery to

the reported recovery times in the booklet. Thus, at six weeks when he did not have the reported range of movement in his knee, he forced it to achieve this range, causing further damage to the knee:

> *Mr T: you sort of get this book and it tells you what exercises to do, and I done all them and it says after three weeks you must come off your sticks and you can bear weight and after six weeks you should be able to walk up and down the stairs normally.. well I can't walk up and down the stairs normally after 6 months. When I went to see the doctor, you could almost feel the heat there.. he said 'what have you been doing to this knee' and I said I have been trying to bend it by pulling it back and I force that up.. hour after hour I used to do that.. 'you are over-exercising it', he said 'just take it steady, don't exercise at all, just walk the normal, go for a walk'. I think I was thinking the more I get it on the way the better, I said you don't get any gain without pain and I don't want any more operations.. he said 'not in this instance, you have over done it'* **(66, *divorced male, retired, previous operations*)**

## Summary

The majority of the informants were still experiencing pain and immobility six months after their operation. However, rather than state that the operation had been unsuccessful, they claimed that the outcome was positive. They provided a variety of reasons to explain why they had not achieved a completely successful outcome. Many blamed themselves for the remaining pain and restriction of movement, or believed that the recovery process was not yet complete. There was also a sense of relief that they had coped better with the TKR than anticipated, and also a feeling of gratitude that the operation had been performed. Furthermore, as all of the informants did experience a degree of improvement in their symptoms, they were pleased by their better quality of life, and the majority of them anticipated yet further improvement as the recovery process continued. Thus, the majority of the informants, as a result of these explanations, continued to consider the TKR with high regard, whilst still experiencing considerable pain and disability. These issues are considered further in the next chapter.

# CHAPTER 8: DISCUSSION AND IMPLICATIONS

## Introduction

In this chapter the empirical findings contained within chapters 6 and 7 are drawn together and discussed in the context of the existing literature. The first section discusses the experience of OA in the context of older age. The second section elucidates the informants' help-seeking behaviour and their views of referral and listing for surgery. The third section explains the findings regarding the informants' expectations towards their TKR, while the fourth section examines the perception of TKR outcome, from the patients' viewpoint. The fifth section provides a discussion on the methods used and the possible impact on the findings.

## Experience of Osteoarthritis

This study confirmed that OA is perceived to be a chronic and debilitating condition[11,16,38,138]. The effects that OA had on the informants were wide-ranging. The most commonly perceived symptom was pain, although it was not necessarily the most important[129,186]. The informants also experienced stiffness to differing degrees, and all symptoms varied according to time of day, the weather, the previous day's activity, level of use and how tired they were. The difficulties that the informants experienced were put into the context of what they could and could not do. For example, they spoke about the pain preventing them from working or participating in leisure activities or hobbies, and its impact on their ability to leave the house or do housework. The emotional impact of OA was also discussed revealing the frustration and depression that the pain and disability caused. The fatigue, loss of independence and control over their lives were also highlighted as major problems, and the unpredictable nature of OA led to fear of doing activities. However, despite the major impact that OA had on their lives, they did not view their joint problems to be an illness. For the majority, OA was viewed as a physical disability, an inconvenience, or something to put up with as a part of old age[138,186,323].

Major sociological theories have relevance to this study. Bury argued that the meaning of an illness can be defined in terms of its 'consequences', which refers to the impact it has on practical aspects of the person's roles and relationships in everyday life; and in terms of its 'significance', which relates to the cultural connotations, the symbols and

significations, surrounding different sorts of illness and disability[124]. In his study of people with RA, Bury noted that much of the 'biographical disruption' relating to the diagnosis of RA was owing to the image of arthritis as an old persons' disease and the 'premature ageing'[158] that this implied. Quite the opposite was true for the individuals with OA in this study: OA was not seen as 'premature aging' but as an inevitable process of ageing. The obvious reason for this disparity lies with the different aetiologies of the two conditions. The main distinction is that RA patients tend to be younger (the reason why RA sufferers view their arthritis as a 'premature aging'[158]), and the onset is generally more rapid with systemic effects. The onset of OA tends to be gradual and commonly becomes symptomatic in the 6th and 7th decades of life. Thus, OA was perceived to be a 'wear and tear' condition and it was deemed 'normal' to experience joint pain and disability in older age. This finding confirms other sociological studies of OA[134-138]. However, despite the common view that OA is common and inevitable in older age, most of the informants were distressed at the prospect of being perceived as old or disabled. Therefore, in terms of the connotations or 'significance'[117] of OA, although the informants recognised a certain inevitability about the condition, they tried to disassociate themselves with this image[153,131]. They went to great lengths to mask their symptoms from others to maintain a positive self-image. Thus, despite the fact that OA was not seen as 'premature ageing', and was common in older age, informants were still distressed about the fact that they had a condition which symbolised their old age. In terms of 'consequence'[117], the symptoms of OA (pain, disability and stiffness) were also described as a major disruption in their daily lives.

Despite the informants' general acceptance that OA was age-related, they attempted to explain the onset of their OA in the context of events in their lives. They highlighted a number of general and specific factors from their life history, which were thought to have predisposed them to OA in later life. For example, accounts depicted OA as a result of joint over-usage from factors including excessive sports performed as a child, the sustained effects of manual occupations, or hereditary factors. Specific events, such as sport injuries, accidental falls, road traffic accidents or events that occurred during World War II were also raised as possible reasons for the onset of their OA. Although all informants provided specific and general explanations for the cause of their OA, some were more descriptive than others. In some instances, informants imputed a

single particular incident or event for the cause of their OA, whereas others provided a range of possible general reasons when no definite specific occasion was available. Previous sociological work has documented that the way to sustain a sense of life course is through a 'narrative reconstruction' of events leading up to and through the illness[122,156,401]. The 'illness narratives' provided by the informants in this study illustrated the various reasons on the nature of disrupted experience, its meaning and actions that were taken to deal with the condition.

One major pitfall of having a 'normal' condition that commonly occurs in old age was the lack of recognition of the severity of the symptoms by other people. Most of the informants spoke of the lack of understanding on the part of their friends and/or family, and became upset by inconsiderate statements such as *'it's only arthritis'*. The majority believed the severity of symptoms of OA are only truly understood once they have been experienced: if OA has not been experienced, it is likely to be dismissed. The additional fact that the pain and physical signs of OA are largely invisible to others caused the informants distress, as they felt their symptoms were concealed and therefore insignificant. The fact that the course of OA *'creeps up'* over many years, led individuals to make certain adaptations, and this adaptation may also contribute to the lack of recognition of severe symptoms. These issues have also been raised in previous research on OA[402].

Social gerontologists have pointed out that the predominant image used to describe ageing and elderly people in society are negative stereotypes[403]. This is exemplified by the image presented on the street sign which depicts old people as being crippled and using walking sticks[80]. In order to avoid falling into this category through illness, the informants in this study attempted to hide or 'cover up' their symptoms and 'pass' for being 'normal'. Therefore they resisted the use of walking aids, wore particular clothes which helped cover the knee, and did not reveal the pain they were suffering when in company. This is common in people suffering from chronic illnesses of various types[120,131,153,155]. Informants also compared themselves with other people who were 'worse off' than themselves. This process of 'downward social comparison'[404,405] is thought to have a favourable impact on the self[202]. These views have similarities to research findings which suggest that people often compare themselves to others worse off than themselves to help them cope with their condition and also to present a positive image of 'ageing well'[138,406,407].

All the informants worked out ways to cope with their arthritis. Previous work on coping with a chronic illness demonstrates the variety of coping mechanisms, strategies and styles of adjustment which individuals develop when confronted with chronic illness[124,125,200]. All informants tried to cope with symptoms by changing the way they did things. They changed their priorities and adapted their activities. However, the main coping strategy was to 'fight' the arthritis. Self-control and a refusal to be *'beaten'* by their OA were cited often and they stated it was important to remain active and pursue and concentrate on activities that they could still accomplish. Informants maintained their positive outlook by their stoical attitude and comparison to others, which helped them come to terms with their OA and endure the pain and disability. These informants stated that they hardly ever got depressed as a result of having OA. Previous research on coping with OA also highlights the use of these confrontive coping strategies[135,220,221]. Other informants stated that they were very depressed by their situation. These informants tended to be those who were more resigned to the fact that nothing could help them relieve the pain. These palliative patterns of coping have been shown to exist in OA elsewhere[408].

Family relationships have been identified in the literature as playing an important role in how the informants deal with their OA and how they can be both a source of support and conflict in the event of chronic illness[127,131,149]. The majority of informants in this study lived with their spouse or a member of their family and discussed the impact of their symptoms on relationships with their extended families. Informants spoke of the support and understanding their spouses gave them and emphasised the positive effect this had on their management of their OA. However, some aspects of the family relationship resulted in negative effects, including feelings of guilt about the transference of household chores to their spouses, and the increasing fear of dependency on their relatives. This fear of dependency has also been found in social studies of ageing[138,407,409]. In addition, the fatigue and frustration of having OA led some informants to become irritable and argue with their spouses as well as rejecting help from the occasional *'unbearable over-protectiveness'* of their partners. The experience of OA led some informants to withdraw from their usual social activities. Some informants mentioned the frustration of not being able to participate in 'normal' activities which therefore made them withdraw and feel less inclined to leave the house. Previous studies have demonstrated how people with chronic illness experience disruption in the social lives and relationships which can lead to a withdrawal of their usual lives[138,149].

Although the medications eased the pain of the OA many informants had concerns about the side-effects, and image of addiction and 'lack of control' associated with tablet taking. As a consequence, some adjusted the dose of their drugs in certain ways (usually by limiting the number of tablets taken) in an attempt to regain control over their life. This supports previous research which suggests that non-compliance with medication is a rational process and legitimate in the eyes of informants[185-187]. Alternative therapies were also used as a substitute or supplement for their GP prescriptions.

## Pathway to surgery

The description of the pathway to surgery elucidated a number of potential barriers that individuals faced when seeking help for their condition. They described their own reasons for seeking help, and their opinions about the GPs' decision to refer and the consultants' decision to list for surgery. These findings reflect previous work about the decision-making process where barriers to utilisation might exist[80].

As the majority of individuals in the study viewed their OA as a 'normal' process in the context of ageing, one third stated that they delayed seeking medical advice at the onset of their OA. The main reason given was that they believed they could tolerate or endure the pain and disability of OA and felt that little help could be offered to them. Previous studies have also demonstrated that people tend to be pessimistic about treatment for their arthritis because of the perceived age-related inevitability leading to a reluctance to seek formal health care[80,138,142,143]. Other reasons given for delaying medical help included a general dislike of going to the doctor, embarrassment of having to seek help, or the intrusiveness of the examination. In addition, 'downward comparison'[405] led to some feeling less inclined to complain or ask for help.

One of the main reasons for seeking medical help given by the informants was the perceived increase in severity of symptoms to the point when they could no longer be tolerated. Over half of the informants stated that they sought medical advice only when their symptoms were such that they were unable to walk or were in severe pain. Statements such as *'I had to go, I couldn't bend my legs'*, or *'I couldn't hardly walk'* were given as triggers indicating the decision to seek help was dependent on the informant's perception that symptoms were sufficiently severe to warrant treatment. Reasons for not seeking help until the symptoms were so severe may be due to the fact that conditions such as OA often worsen slowly over time and individuals often have the

time to adapt to their altered situation. However, there comes a stage when the symptoms become so severe that the individuals are no longer able to adapt to their situation, and this may trigger the decision to seek medical advice.

Over a third of informants stated that it was only when the knee *'literally collapsed'* or *'gave way'* that prompted them to seek help. It is likely that these informants would have carried on without seeking help from their doctor if their knee had not 'given way' or been injured. In addition, a small number of informants stated that they would not have sought medical help for their knee had they not been persuaded to by their family. Similarities can be drawn with previous research which states that the presence of social sanctioning can affect help-seeking behaviour, as well as the importance of recognising symptoms and the interference of symptoms[144,145].

An interesting theme to emerge from the data was the informants' perception of the effectiveness of TKR. The informants were more likely to state that THR was a more effective operation than TKR. This reflects the literature which suggests that in the UK many people still regard knee replacements as being more experimental and less likely to be successful than hip replacements[410]. The overall view was that TKR was seen as a more difficult operation to perform than THR and therefore was more likely to result in worse outcomes. Thus, the prospect of having a 'risky' operation such as a TKR may have hindered some of the informants' decision to seek help although this was not explicitly given by them as a reason for delaying medical help. However, despite the fact that TKRs were seen as inferior to THRs, attitudes towards TKR seemed to be slowly changing: the majority of the informants believed that there had been improvements in TKR in the past decades. This may reflect an improvement in TKR operations or may reveal the informants' optimistic view of a good outcome for themselves. Although Dieppe *et al* stated that there may be a long lag period before better outcomes become accepted by primary care physicians and the general public[80], these results indicate that this shift towards more positive views about the success of TKR has started.

The majority of informants were managed initially by their GPs. Most informants discussed the usual management of knee OA[53,82], which tended to follow a sequential approach, starting with education and advice about exercise, footwear and weight reduction, the use of analgesics and physical therapy, NSAIDs, intra-articular injections, and finally surgery. This process tended to occur over a number of years. Three informants did not experience any trouble being referred, whereas nine informants

stated that they believed their GP was reluctant to refer them to the hospital. This supports previous research which suggests that a major barrier to the utilisation of TJR lies with the GP[80,411]. The reasons given for this perceived reluctance included the GP's opinion of the severity of the knee OA and their attitudes about the outcome of conservative management and surgery. For example, some informants stated that their doctor was more in favour of other (non-surgical) treatments, or that they did not believe their symptoms were severe enough for referral. These have also been highlighted as possible reasons from a recent consensus and literature review[80]. The authors stated that although the severity of the knee can be assessed clinically and with the use of self-assessment tools or radiographs, such instruments are rarely used in primary care. As such the severity of knee OA may often be under-estimated.

In the current study, although reasons for referral were thought to be determined predominantly on the basis of x-ray evidence, in a minority of cases the GP appeared uncertain about the extent of damage shown on the x-ray. For example, in one circumstance, referral was approved in order to be *'on the safe side'*. Previous work suggests that many GPs lack confidence in the examination of the knee joint. This may play a part in a delay in diagnosis, as well as the lack of ability to assess the severity of the knee joint[80]. A possible explanation for this lack of confidence is that in general there is little training in modern rheumatology and orthopaedics in a doctor's undergraduate and postgraduate training[80,411,412]. Another possible reason for a delayed referral was the general negative attitude held by some GPs about the treatment of OA in older people, and a perception that TKR is a 'risky' procedure with a high failure rate in comparison to THR.

The informants discussed their views about the consultants' decision to list for surgery in great detail and raised issues concerning the priority and indications for surgery in general. Little exists in the literature about patients' perspectives on listing for surgery. Drawing on their own experiences, the informants expressed strong views about what they thought *should* happen in the decision-making process, and distinguished this from what they thought *actually* happened in practice. In general, the informants agreed with the consensus criteria that pain and disability should be key factors on which to prioritise people for a TKR[104,105,110,112]. In addition, the informants thought that the decision making process should also include factors specific to the patient's circumstances, including the length and degree of suffering, whether there was a chance

of getting back to work, whether the individuals had dependants, and whether the individual had paid their national insurance. Although two of the consensus-based criteria do specify issues such as work/age and carer issues[110,112], these informants wanted them to be given greater importance and utilised in practice. In contrast, they thought that decisions for TKR were being made according to age, weight, how loudly the individual shouted, and how much money there was in the system. There is some evidence to support these claims. Proportionally, TKRs are not often performed on those below 60 or over 80, and patients are often turned away on the basis of obesity[80,413]. The main concern about operating on young people is the risk of early loosening of the prosthesis[414], and concerns about older people revolve around the risk of complications[415]. The informants interviewed in this study argued that if you have bad pain you should have the operation early to gain more years of benefit, even if it does not last.

The informants' views about weight were at odds with surgeons. Surgeons told the informants to lose weight and that the obesity caused the arthritis. However the informants believed that it was the other way round and that they needed a joint replacement in order to be more active to lose weight:

> *Mr P: at first he said about my weight and I said 'I haven't been able to get around much lately and I have been less active, you know, more weight put on' and he said 'well maybe we ought to do it again later on', and I said 'well I'm just going to get worse', cos that's how it got like that.. so that's what he had in mind and I said 'once I get back on my feet and start doing a bit of training again I can maybe lose a bit of weight'.* ***(48, single male, on disability allowance, no previous TKR)***

There is no evidence in the literature to support the contention that obesity or age can result in more failures or complications[103,333,415-419]. Other recent data suggest that patients with the most severe disease at the time of TKR improved to a similar degree to those operated on earlier, meaning that they never 'caught up' with those who were less disabled at the time of the TKR[420]. These data also show that the oldest people having an operation usually benefit a great deal, but not as much as younger people. Such findings appear to accord with the views of the informants who argued for earlier surgery and no upper age limit.

In the absence of clear indications, the decision to list a patient for surgery is a complex process, requiring the surgeon to consider a variety of factors relating to the individual patient[291]. This may lead to some people being operated on much sooner in the course of

their arthritis than others. The informants in this study highlighted a number of factors which they believed affected their listing for surgery. However, in the absence of the surgeons' views, this must remain speculative. In particular, one issue emerged as important. There appears to be a lack of communication between the consultant and patient. In this study, the reasons given by the consultant for not listing were often not made clear to the patient. For example, despite there being no evidence in the literature for differences in success rates for people in different weight categories, informants reported that consultants gave 'weight' as a reason for not listing for surgery. This was further illustrated by one informant's account of listing in private and NHS care: weight issues were not discussed in private practice. In terms of age, the informants did not consider the risk of revision surgery that may become necessary if surgery occurs early. In addition, although surgery produces excellent results knee arthropathies are most vulnerable in those who wish to dance or walk up or ski down mountains[84]. A more open dialogue between consultant and patient may help the patients understand and accept the decision.

## Expectations, hopes and preferences

Within the literature it has commonly been stated that expectations play a central and dominant role in influencing satisfaction[231,234-236,239,421], although the nature of this relationship remains unclear (see Chapter 3, page 75-80). The different questionnaires and methodologies used to elicit patients' expectations could be one explanation for the lack of consensus between these studies. As outlined in Chapter 3, most of the quantitative studies reported that their patients were able to describe their expectations of an outcome, via the use of questionnaires, rating scales or open-ended questions. However, previous qualitative studies (using semi-structured interviews) found the opposite: individuals actually found it difficult to identify or articulate their expectations. This study also used a qualitative methodology to explore the nature of expectations. What emerged from the data was very different to the previous quantitative studies, but similar to previous qualitative studies. The results from this study highlighted a number of problems with the concept of expectations and demonstrated its complexity. This complexity has also been demonstrated by other qualitative studies exploring patients' expectations of consultations or surgery[245,260,284,290].

A major issue was the difficulty encountered by the informants in expressing expectations. For example, when asked to state their expectations about the outcome of

the TKR, most of the informants found them difficult to articulate and were generally evasive and noncommittal in their replies. They often began with a disclaimer such as *'I don't know until the times comes'* or *'I'm not expecting anything'*. Thus, the informants found it difficult to describe or classify their expectations in any simple manner. The informants tended to talk about what they *hoped* would happen, rather than in terms of what they *expected* to happen. Thus, informants were hesitant to express definite expectations and were more likely to say *'I hope for pain relief'* rather than *'I expect pain relief'*. Expressing hopes and fears about the operation rather than expectations also supports previous qualitative work on expectations[239,245,284,290].

At the pre-operation interview, the majority of the informants generally held two types of hopes: 'ideal' hopes and 'pragmatic' hopes, reflecting both the optimistic view of the outcome and the probability of achieving this. This dichotomy of concepts mirrors some of the definitions of expectations already investigated into the literature[237,239-243]. For example, expectations have been divided into 'ideal' expectations which represented the individuals' aspirations, desires, wants or preferred outcome, and 'predicted' expectations related to what the individuals actually believed would happen in a medical encounter. In this study, an 'ideal' hope reflected an optimistic view of the operation and justified going ahead with the operation. Ideal hopes revealed the informants' ultimate wish: to be completely pain free and have increased mobility leading to a return to 'normal' life. The majority of informants however, qualified their 'ideal' hopes with a 'pragmatic' statement, which illustrated their reservations about achieving this 'ideal' hope. These 'pragmatic' hopes were clearly guided by the informants' previous knowledge, experience and lay beliefs about factors which may affect their outcome and recovery. A small number of informants were extremely pessimistic about the outcome of the operation, despite having an ideal hope for its success, whereas seven other informants did not qualify their ideal hopes and thus tended to view the TKR as a 'miracle cure'.

Expectations are referred to as 'the action of mentally looking for some one to come, forecasting something to happen, a preconceived idea or opinion with regard to what will take place'[422]. Hopes are referred to as an 'expectation of something desired'[422]. Although the concepts have similarities, hopes tend to be based more upon emotions or wishes, things that individuals want reality to be, whereas expectations tend to rely more heavily upon rational thought and logical reasoning. Thus, the informants in this

study were not able to 'forecast' what they thought would happen, but were only able to theorise their hopes and fears.

Informants were asked to give reasons for expressing hopes and fears as opposed to expectations. A number of informants were unable to express any firm expectations as they did not know what was going to happen: they had received little information about the operation and its outcome. 'Unformed' expectations have also been highlighted in the psychological literature[237]. Another possible reason for these 'unformed' views may be due to the fact that individuals could only understand and express what they had expected after the experience had occurred. This was borne out by the findings of this study and demonstrated that it was only at the post-operation interview that the informants were able to describe their expectations (what they really thought would happen), in the light of what actually occurred in the hospital and operation process. This reflects interpretative sociology which states that individuals cannot know definitely what will happen before an experience[298]. Schutz stated that meaning is found in the reflective glance that individuals cast on actions and acts that have been completed. Thus, meaning is the end result of an individuals' interpretation of completed experiences. Schutz (1932) explains:

> *because the concept of meaningful experience always presupposes that the experience of which meaning is predicated is a discrete one, it now becomes quite clear that only a past experience can be called meaningful, that is, one that is present to the retrospective glance as already finished and done with. (p.52[298])*

Thus, all subjective meaning is constituted in retrospect through reflection, rather than in the present moment of lived experience. The meanings of actions are thus reconstructed retrospectively on the basis of memory, they are not given in an immediate way[298]. As a consequence, individuals routinely make sense of events by interpreting them in the context of their existing beliefs when they have had time to reflect upon its impact and consequences. Stimson and Webb (1975) also reported that often it is only in retrospect and evaluation after the event that the person begins to formulate ideas of what they were really expecting[239].

In this study, Mrs M stated at the pre-operation interview that she hoped the knee would be better, although she was aware that her age may effect the outcome: *'well I am hoping the knee will be better but I can't say that can I, because I am older now and I suppose age has got a lot to do with it'*. However, it was only at the post-operation interview that she

made comments such as *'I thought it was going to be a lot quicker, I thought I would be up and about and ready to run again .. within about 6 weeks at least'*. Thus, the informants had hopes and fears before their operation but only articulated what they had expected once the experience had passed. This has important implications for research which suggests that satisfaction is influenced by the fulfilment of expectations. The fact that many realities are unanticipated means that individuals may not know what to expect. Therefore, expectations cannot be used as a starting place on which to base an assessment of the level of satisfaction.

An important question remains: why do quantitative studies demonstrate that patients have clear expectations about the outcomes of surgery, but qualitative studies tend to report them as tentative, vague and even non-existent? One reason may be due to the limitations of questionnaire design. Simple and direct questions about expectations may result in simplistic answers. As shown in this study, informants were reluctant and found it difficult to answer direct questions such as 'what do you expect from the TKR?'. In addition, the limited fixed choices provided in questionnaires or the few open-ended questions about their expectations may have led some patients to 'pigeon-hole' responses or express a view which did not represent or capture the complexity of this concept. Qualitative studies, however, retain the complexity and contradictions in the analysis and therefore explore in more detail the context in which statements are made. Furthermore, the settings and conditions under which the questionnaires, rating scales are conducted may affect the views and answers given. For example, responses may differ depending on whether the patient is being asked about their expectations by their doctor or nurse, or whether the study is being undertaken in a hospital, outpatient clinic, private office as opposed to the patient's home or place of work. An individual may feel pressurised or obliged to give an answer that is publically acceptable. It is thus important to socially contextualise research in order to know how to interpret the meaning of findings which are obtained.

One of the ways in which the informants found it easier to express their thoughts about the outcome was to ask them about the importance of a particular aspect. It is generally suggested that TKR is undertaken by surgeons to relieve pain and is a key component of the health status of a patient who has arthritis[423]. However, when the informants were asked to choose what they would prefer, the majority stated that being mobile was more important to them than being out of pain. Reasons for choosing mobility rather than

pain relief included the fear of dependency on others, care-giving responsibilities, the desire to be active and pursue activities, and the belief that pain can be controlled/endured. This suggests that informants give greater priority to the continuation of their pursuit to be independent than the relief from pain.

The way that expectations and subsequent experience interact to affect satisfaction has been given substantial consideration in recent years in health services research[234,241,242,246,297,421]. Despite the inconsistent and often contradictory relationship between expectations and satisfaction, as well as the differing definitions given to expectations cited in the literature, expectations continue to be regarded as a valid concept and are a criterion used to evaluate care: they are thought to enhance the ability to assess outcomes and patient satisfaction[297]. However, one of the main original findings from this work illustrates that often an individual does not have clear and definite expectations about an intervention beforehand. As this study suggests, expectations cannot be documented or classified in any simple manner. A better construct may be to record the main hopes and fears of the patients and then set these in the context of the post-facto rationalisations.

## Perception of outcome

This study has highlighted a number of important issues in relation to the effectiveness of TKR. As stated in Chapter 3, TKRs are reported to relieve pain and improve mobility with the best published results reporting a 'good' or 'excellent' outcome in approximately 90% of patients[90]. These assessments were derived from quantitative studies. However, this qualitative study found that despite the outcome being expressed in positive terms ('good', 'very good' or 'excellent'), the majority of informants continued to experience pain and restricted mobility six months after the operation. Previous research has also highlighted similar findings where patients continued to have symptoms but expressed themselves as satisfied[247,424]. Indeed, a consistent finding in the UK and US is that only a minority of respondents are generally dissatisfied with health care and treatment[260]. Analysis of the case studies of the informants interviewed post-operation provided an insight into the reasons behind these apparently contradictory statements.

As patient satisfaction is a multidimensional concept, the method of questioning is very important. The results from this study demonstrated that global questions about the

satisfaction with the outcome resulted in a positive overall view of their TKR outcome and experience. For example, of the ten informants interviewed post-operation, nine stated that the TKR outcome was either 'excellent' (2), 'very good' (3) or 'good' (4) when asked their view of the outcome. For example, in response to global questions such as 'how satisfied are you with your TKR outcome?', informants made statements such as *'it's all been very good'* or *'excellent.. no complaints'*. Thus, they appeared to summarise many aspects of the treatment process into one response. It was only after further in-depth questioning that the informants admitted to the limitations of their TKR outcome. Thus, questions, which asked specifically about their outcome, allowed the informants to indicate their views about the symptoms that they still experienced. For example, eight of the ten informants admitted to the continued experience of pain and/or immobility, after previously reporting a 'good' or 'excellent' outcome.

Previous literature indicates that patients hold distinct views with regard to the technical, interpersonal and outcome aspects of their health care, thus, the use of a single global score disguises the complex nature of satisfaction[424]. Even when multidimensional scores are used, summary scores are usually taken, whereby the scores of the different dimensions are added together giving equal weight to different aspects of satisfaction. This does not make it easy to detect contrary trends between dimensions (for example, patients may be satisfied with staff interpersonal skills but dissatisfied with the outcome). Thus, data gained by questionnaire methods (which tend to use global ratings of satisfaction) may miss important aspects of patients' views or fail to capture individual meanings or reasons. Qualitative methods on the other hand help to clarify these sorts of issues with further insightful questioning. This has implications for the evidence of TKR as an effective operation, as the main outcome measures tend to be global rating scores, which obscure variation.

It also appeared that direct questioning about the outcome resulted in the informants giving a socially desirable answer and being positive about the TKR outcome. This can be seen as their 'public' expression of their outcome. This may be as a result of responding to a formal question, perhaps in the same way an individual might respond to medical staff or a questionnaire. Individuals responded in simple terms and provided a summary of their experience. However, it was only after further in-depth questioning that the informants described in more detail the qualification to this global outcome and discussed the limitations of their outcome. This 'private' expression was more about

their discomfort with the difficulties they were still experiencing. In the 'private' account, informants were more willing and able to describe in further detail the overall summary of their outcome. They were given time to focus on what they could do and could not do on a day to day basis.

Other social researchers have attempted to account for conflicting views presented in interviews[138,163,407]. For instance, Cornwell also claimed that her respondents gave two different types of accounts: private and public[163]. She felt that the private accounts were indicative of people's real views, but they often felt obliged to present a publicly acceptable point of view. She stated that 'what people say, and how they say it, varies according to whom they are talking to and the circumstances in which they find themselves' (p12[163]). For example, in the presence of an interviewer perceived to be an expert, individuals are more likely to talk about their illness experience with reference to institutions and authorities. However, when the interview was made more informal, patients were encouraged to 'tell stories' and the illness experience is intimately woven together with biographical information about the speaker. Thus, the public accounts may represent the 'pat response': the right thing and say, reflecting some image of 'society at large' or what they felt the researcher wanted to hear. Private accounts were more likely to contradict the acceptable view and were thought to represent the 'true feelings', incorporating a range of psychological, emotional, social and contextual influences. It was only through the process of establishing an equal relationship between researcher and informant that the more complex 'private' voice of their experiences and aspirations could be heard. Within the literature, it has also been reported that patients may not complete quality of life measures in ways that accurately reflect their feelings[206]. For example, patients may seek to answer questions in ways that present themselves favourably.

This has particular relevance for this study that illustrated that informants held both a 'public' ("excellent") and 'private' ("not so good") view of their outcome. It may be that in questionnaires completed in the quantitative studies which reported TKR to be a highly effective intervention[91,318,340-343], the informants only expressed their 'public' view of the outcome. The 'private' expressions that there was still the remaining pain and immobility may only be captured using a qualitative approach.

The distinctions between 'public' and 'private' accounts of health and illness have been further analysed in the literature and yield valuable insights[425]. For example, Cornwell

presented the 'public'/'private' distinction as if people were using different rhetorical strategies[163]. However, although there is a claim that the distinctions emerge in different contexts, no definite criteria were presented[425]. The implication is that the 'private' account is more authentic or nearer the 'truth'. Radley and Billig challenge this and argue that there is little essentially private in the 'private' account, just as there is little essentially public in 'public' statements about health and illness[425]. The 'private' account contains its own public dimensions: 'the private person is appearing as a public person, behaving so in private' (p.231[425]). Thus, stories are never merely stories, especially when it comes to matters of health and illness: '... people use health beliefs to make themselves accountable *to others* and to articulate *for others* their own position in the world' (p.222[425], italics in original). Thus, the search for some single, unbiased truth may be seen as fruitless, since it either does not exist, or it cannot known in any meaningful sense, or that in fact there are multiple contradictory truths[367]. Therefore the impressions that people try to create for each other and for the observer should be treated as valuable sources of data in themselves. The focus should be upon the social setting in which the research takes place, rather than using accounts gained through research to explain behaviour in settings where the researcher is *not* present. Thus, during the process of research, the informants and researcher create a social world, rather than representing some independent reality and that his/her world is not more or less true than others[385].

An important question remains concerning the implications for indications of outcome and health status: which of the two accounts ('public' or 'private') should be taken as superior? The answer to this is that both should be considered or at least the possibility of the existence of multiple realities should be taken into account. The 'public' response represented an immediate and summarised formal response whereas the 'private' expression enabled the informant to qualify their global response. They acknowledged their improvement and desire for a good outcome and indicated that it was good in their 'public' view. This is true because all of the informants had improved as compared to their pre-operation condition. However, when allowed time to describe their summarised outcome in more detail, they then qualified this with statements about the remaining pain and immobility. Structured questionnaires fail to capture this qualification. The existence of these two realities does not mean that one is superior over the other, but it represents two different ways of portraying the same thing. Capturing only one of these accounts provides only one portrayal of the experience, whereas as multiple realities exist, these should be explored in depth as well.

## Outcome of total knee replacement - a rationalised outcome

A fundamental finding of this study was the process by which the informants struggled to understand and adapt to their outcome. All of the ten post-operation informants provided rationalisations and adjustments in response to their perception of a difference between their hoped for 'excellent' outcome and the continued pain and disability. They attempted to make sense of their disappointment with their remaining pain and disability.

Numerous explanations were given by the informants to justify having had the operation. The very human desire to say they had made the right decision in going ahead with the operation emerged as an important theme. For example, many stated how grateful they were to have the operation which they had waited so long for. They were pleased that the operation had been performed and that something had been done to relieve (at least) some of the pain and disability they were previously experiencing. As such, their lives had improved and they were able to do more activities than before the operation, although not to the full extent. In addition, the fact that the majority of informants felt they had coped with the operation better than expected led to them feeling positive about their outcome.

The process of 'downward social comparison' also reminded the informants that they had adjusted to their TKR outcome better than other people they knew[404,405]. Statements such as *'I got away pretty lucky'* were cited when comparisons were made to other people with worse outcomes. Others compared their healing process with other people's and acknowledged and accepted the fact that they had a slower healing time due to their age or genetic makeup. Many held the continued hope for improvement as they felt that the recovery process was not complete after six months. Thus, they felt they needed more time to improve and achieve the full benefit of the operation. However, the evidence suggests that if an individual has not achieved pain relief or mobility at approximately six months, then they are unlikely to improve any more[420,426].

The overriding rationalisation for remaining pain and immobility was that it was their 'fault' as they had either over-worked the knee too soon or had not listened to the information given about the recovery. This self blame may represent attempts to re-establish some control over the outcome of the TKR. There was never any criticism of the surgeons or the surgery for the remaining symptoms. Other researchers have

observed individuals' reluctance to express criticism for the NHS or health professionals, resulting in a so-called 'normative effect'[247,424]. One of the reasons given for this reluctance arises from a sense of sympathy or understanding for the constraints that prevail in the NHS; it would be unreasonable or inconsiderate to criticise.

The fact that all of the informants made rationalisations about their outcome has important implications for the literature that asserts the relationship between expectations and satisfaction. This study has already highlighted particular problems associated with expectations (see section above). The additional fact that the informants adapted to their outcome raises further complications for this relationship. Based on the literature, it could be suggested that those informants expressing only 'ideal' hopes for the success of the TKR would be more disappointed with the remaining pain and immobility, as they had hoped for too much. Similarly, those informants who held 'pragmatic' hopes about the TKR outcome would be more satisfied with their outcome, as they would be prepared for possible complications or an outcome which had limitations.

However, there was no evidence for the former statement; the main reason being that the informants rationalised their outcome depending on how it was perceived, but independent of their hopes. For example, two of the informants who expressed only an 'ideal' hope pre-operation (Mr T, Mr O) were still experiencing pain and restricted mobility afterwards. However, even though their high hopes for the outcome had not been fulfilled, they did not state that they were dissatisfied with their outcome. Mr T, who had high hopes for the outcome of the operation, justified his continued pain and immobility as he believed the recovery was not complete, that his age and other damaged knee had impinged on the full recovery, that he had over-done the exercises, which had therefore affected the TKR recovery. Furthermore, some informants re-interpreted their pre-operation hopes. For example, Mr O stated that he had *'expected too much'* and that his hopes had been too high and unrealistic. These were only stated in retrospect: once he had had time to reflect on the experience[298].

The remaining eight informants who justified their 'ideal' hope with 'pragmatic' hope did not appear to be more satisfied with their outcome. Similar rationalisations were used to make sense of the outcome. However, there were a few exceptions. Three of the informants stated that their outcome had surpassed their hopes (Miss D, Mrs B, Mr S). For example, Miss D stated that she was *'not expecting anything'*, although she did

express an ideal hope for pain relief and improved function. She was very pragmatic in her view of the outcome and was aware of potential complications and the effect her co-morbidities may have on the outcome. At the post-operation interview, she said that it had been *'much better than expected'*. In general, these informants believed it was important to have pragmatic or pessimistic views pre-operation to avoid disappointment and to allow satisfaction with even the slightest improvement.

***Response shift***

A possible explanation for the way that the informants made sense of their outcome may be found in research that has shown that changes in health status may induce changes in the meaning of one's self-evaluation: a phenomenon called response shift[201] (see Chapter 2, page 60-61). In medicine, response shift refers to a change - as a result of an event such as a therapy or an operation - in the meaning of one's self-evaluation of quality of life. Thus, when health fails or an outcome of an intervention has not improved the quality of life to the full extent, individuals are said to reappraise the values and activities that had given their lives meaning[427]. Thus, an adjustment or a redefinition of one's life to accommodate an ongoing disease state occurs[428]. Patients change their internal standards, values or reconceptualisation of quality of life and therefore assess outcome differently than they would have if they had not adapted to their situation. In this study, it was apparent that the informants accommodated their view of the TKR outcome, rather than give a straightforward representation of the symptoms they were still experiencing. This recalibration or reconceptualisation of their outcome becomes a means of successfully coping with their outcome.

Response shift is a particular problem when doing longitudinal research on changes in health status because the implication is that changes might not be 'real': it may be due to the individuals' adaptations and adjustments to their condition[325,429]. For example, within the literature, quality of life ratings have been shown to differ[206]. Having a greater understanding of how patients' evaluations change over time could help explain this disagreement and might aid interpretation in changes in scores over time[206]. The informants in this study certainly appeared to adapt and accommodate to their TKR outcome, reflecting the 'response shift' phenomenon, however, other factors such as their life context were also important.

*Context*

An additional key to understanding the apparently contradictory accounts of the TKR outcome was elucidated when taking into consideration the informant's life context. Examining individual case studies showed that the informants' perception of the outcome made sense in the context of the pre-operation data and the changes that had occurred since the operation.

For example, Mrs L, although in as much pain after as before the operation, stated that she had a 'good' outcome. One of the main reasons given for this statement was that she had recently moved into a friendlier residential home. Before her TKR, she was living alone and admitted to feeling lonely, which intensified her feelings of her knee OA pain and disability. However, after the TKR she had moved to a residential home and was in the company of friends. Thus, she was in a much better frame of mind, and as a result of this better situation and mood, she perceived her TKR outcome in a positive way, even though she continued to experience pain.

Another informant, Mr O, who was also still experiencing pain and restricted mobility, also regarded his TKR outcome as 'good'. After examination of his case study, it was apparent that he was determined to view his TKR outcome as positive as he was wanted to regain his role as a father and provider. He was also aware that he would need revision operations due to his young age and was strong-minded that he would make this TKR work for him. Mr S, on the other hand made sense of his remaining pain and immobility in the context of his religious beliefs. He had gone into the operation with a pessimistic view about the success of the outcome, which reflected his religious belief that you only receive what you deserve from God. Although he was still experiencing pain and immobility six months after the TKR, he thought that the outcome was better than he had anticipated. He believed that this was God's way of trying to improve him as a person. Mrs E was the only informant not able to give a definite view about her outcome. Although she was disappointed with her outcome, she was reluctant to say that it was a bad outcome: she did not have the expected pain relief and mobility but realised that the TKR had improved her situation to some extent. She gave reasons for her disappointment that centred on the fact that she had refused to listen to any information about the TKR, due to her initial fear of the operation.

Thus, consideration of the context in which outcomes are perceived is important as they highlight the complexity of assessing outcomes.

## Summary

This study has shown that assessing TKR outcomes is a complex process. Individuals struggled to understand their outcome and often described their outcome in contradictory terms. They presented both a 'public' expression of the outcome reflecting their socially desired view, and a 'private' expression of the TKR outcome, reflecting their discomfort with the difficulties they were still experiencing. These apparently contradictory accounts were consistent in the context of the informants' lives, and represented an adaptation or accommodation to their outcome. Outcomes of TKR gained by questionnaire methods may only represent a limited view of the patients' perception of TKR outcome and fail to capture individual meanings or adaptations. In contrast, this qualitative work has highlighted the complexity of outcome measurement.

## Reflections on the method

Qualitative research is a method of naturalistic enquiry: the aim is to study people in their natural settings and to collect naturally occurring data. Its main objective is to understand behaviour in the context in which it happens: the focus is on the meanings the participants attach to the social world[370]. This is achieved through a combination of observation, exploration of the ways in which people interpret their experiences, and reflection on the impact of the research process.

Qualitative research is used by anthropologists studying exotic cultures, and social scientists whose approach is based in a phenomenological perspective. The latter argue that qualitative research is less obtrusive than quantitative investigations and consequently does not manipulate the research setting[373]. Furthermore, measurement scales and questionnaires are thought to be unsatisfactory because it is unknown whether all important domains are included and they do not capture the subjectivity of human beings. In contrast, qualitative research allows the informants to raise issues of importance to them, without imposing any fixed choice responses. Qualitative research also seeks to understand an individual's interpretation of their experience, their search for meaning and the importance of context in understanding their perspectives. Thus, interviews are a more flexible method of gathering data, allowing the investigator to respond in an individual way to respondents' interpreting and answering questions. For these reasons, semi-structured interviews were conducted with patients before and after their TKR operation.

The patient's view has, in recent years, been increasingly incorporated into the design of many quantitative studies investigating the outcome of TKR but little qualitative work has been undertaken. The aims of this study were to elicit informants' experiences of living with OA and undergoing a TKR operation. Given the exploratory aims of this study, in-depth interviews were the most appropriate method of data collection. This approach attempted to look beneath the surface of a subject, exploring the informants' own interpretation of their experience and their search for meaning. For example, I have demonstrated that the informants in this study strove to make sense of their TKR outcome and rationalised the remaining symptoms of OA to avoid disappointment. A questionnaire based study of TKR outcome would not uncover this, as the context would be lost.

There are no standardised sample size requirements in qualitative research. Sample size depends on what the research project is attempting to find out, how the findings will be used, what will have credibility and what can be done within the practical constraints of time and resources[375]. Patton (1990) stated that:

> *"The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities than with the sample size". (p185[375])*

The sample size, therefore, should be based on theoretical and informational factors, to maximise the information provided[374,375]. Although there are no pre-determinable sample size requirements for qualitative research, estimates of how many respondents are appropriate have been suggested. For example, between 12 to 20 individuals have been recommended[374,375]. This has been accomplished in this study, having interviewed 25 individuals pre-operation, and subsequently followed ten of these informants for a post-operation interview.

The informants in this study were purposively selected from three orthopaedic consultants' waiting list at one hospital, to gain a range of informants with their respective different consultants. Unfortunately, this endeavour fell short of its potential as one consultant retired shortly after agreeing to participate in the study (one informant recruited), and another consultant did not operate on a weekly basis, so there was a limited number of informants with OA (four informants recruited). Thus, the majority of individuals sampled in this study came from only one consultant's list (20 informants recruited). The fact that most of the informants came from only one hospital and mostly

from one consultant may have clear limitations to the study sample. However, a wide range in age and a balance of gender of the informants were achieved. The sampling procedure continued until no new information was forthcoming from further data collection. Thus sampling was terminated at the point of 'saturation' or 'redundancy'[374,375]. Saturation was attained in the pre-operation interviews and to some degree in the post-operation interviews.

Information about previous TKRs and other co-morbidities were not available from the waiting list cards (only the age and gender of the informant). This lack of information meant that ten of the informants interviewed had already experienced a TJR and it was only at the pre-operation interview that this was discovered. These informants prior experience of a TKR may have affected their views and thoughts about OA and the pending TKR, which would be different from those undergoing a TKR for the first time. Nevertheless, the presence of two groups was advantageous, as comparisons could be made between them. No informants were interviewed who were waiting for a revision operation.

Of the 25 pre-operation informants, ten were interviewed again six months after their operation. Informants were purposively sampled for a post-operation interview to obtain a reasonable distribution of males/females and ages. However, selection of informants for the post-operation interview was constrained by time limits. The time point chosen for the post-operation interviews was six months, which was considered sufficient to ensure that the outcome of the operation was established. Previous work on outcomes of TKR indicate that leaving a period of more than six months for follow-up does not significantly affect or improve the outcome[420,426]. In addition, many of the quantitative studies assessing TKR outcomes typically use a six month time point for follow-up, thus permitting some comparison with this research.

**Rigour**

General principles of good practice for qualitative methods have been developed to establish rigour. Hammersley (1992) advocates that quality should be assessed in terms of its validity and relevance[385]. The qualitative research undertaken in this study conforms to many of these suggestions. For example, a full description of the research methods used and the process of data collection and analysis were provided (Chapter 4, page 94-108). This enables the readers to assess for themselves the evidence upon which

interpretations were based with reference to how the evidence was collected. Investigator triangulation[391] was achieved through the independent assessment of transcripts, interpretations and use of quotations by my advisors. Simple counting was also used a helpful indicator how significant and comprehensive a theme was[394]. Source triangulation was used by the provision of one or more quotations in support of a particular theme. In addition, the presentation of data was based on 'fair dealing'[430] and attempts were made to avoid excessive selectivity of the informants and included a range of quotations from all informants. Deliberate selections of negative cases were also represented to describe the variability in the informants' views. Although respondent validation (feeding interpretations back to the respondents for verification)[374,394] was not utilised in this study, many of the informants at the post-operation interview reiterated much of the pre-operation information, confirming veracity of their accounts.

Generalisability is not usually considered to be an aim of qualitative research. However, it has been suggested that it can be assessed by considering the typicality of cases in relation to the general population[351,377]. Lincoln and Guba referred to generalisability as 'transferability[374]. Although it would be impossible to state that the small sample in this study was representative of all those who undergo a TKR, their demography corresponded well with the general profile of those operated on in the UK[85,420]. However, consideration of the decision to participate in the study must be addressed. Of the 40 patients contacted from the waiting lists, 25 gave their consent. Reasons for participating were often discussed, and a number of informants felt it was their duty to get involved and support research performed in the NHS. Others felt obliged to participate as they believed that if they did not, it would delay the timing of their operation date. A small number also felt that this was a normal part of the TKR process. Thus, the group of informants included in this research may have been more proactive in their view to research, or more wary about refusal to participate believing that their operation date depended on it, than the others who chose not to participate. The remaining 15 patients either did not reply to the letter (10) or refused to participate (5). Reasons for refusal for both groups were not obtained. Reluctance to participate may be due to different factors than those indicated by the informants here.

The interpretative strategy employed within this study used components of grounded theory and thus an iterative, cyclical approach to the analysis of the data was carried

out. The analysis of the data was a difficult task as the informants produced very complex and often contradictory accounts concerning their perception of the TKR outcome. As a consequence it took a number of different approaches within the analysis of the data to uncover their 'struggle' to come to terms with their outcome. The analysis of these data required a detailed examination of the interviews, a search for negative cases and the development of detailed case histories for each of the informants interviewed post-operation. Examination of the case studies proved very important as it became clear that the informants' contradictory accounts about the outcome of the TKR expressed at the post-operation interview made sense and were consistent in the context of their pre-operation views. At each stage these data were examined by my advisors.

## Reflexivity

A major issue in qualitative research is how the researcher presents themselves to informants and how this may affect the interview. This is important 'because after one's presentational self is "cast" it leaves a profound impression on the respondents and has great influence on the success (or failure) of the study' (p.367[378]). An essential requirement is that interviewers be perceived by respondents as neutral with regard to the subject matter of an interview[400]. However, the researcher may have a number of different identities, and therefore personal characteristics may have an impact on the interview.

A number of factors may have determined the type of interaction I had with the informants. For instance, being a young woman interviewing older adults may have affected how open or relaxed I felt with them and vice versa. At the start of the interviews, I presented myself as a research student from the University who was interested in hearing about the informant's experiences of their OA and TKR. I admitted to a lack of knowledge of the subject matter and emphasised my student status and interest in learning more about their experiences of OA and TKR. However, it was apparent from the interviews that the informants viewed me in varying ways, ranging from a 'health visitor', 'young lady from the university', 'medical student' or 'medical doctor':

> *Mr S: I call you the health visitor, that adds up to it.. it is in a away, you are into health, not a normal health visitor but same sort of job.* ***(64, married male, retired, previous knee operations)***

*Mrs I: so are you one of his little satellites that go behind him [consultant] and listens, I know.* ***(71, married female, retired, previous TKR)***

On a number of occasions I was asked to state when their operation date was and also for medical advice. In addition, as all the informants were expecting to hear when their operation date was due, I had the impression that a number of them viewed my visit as a check-up appointment to see if they were ready/worthy for a TKR. This was apparent when the informants were completing the two questionnaires. Comments were made when completing the questionnaires stating that they thought the consultant would look at the questionnaire responses, and decide to operate on the basis of their answers.

*Mr W: if I put extreme, he'll probably get me in straight away… but I'm not doing it for that I am telling you the absolute truth (I: and the thing is as I said it's completely confidential, he won't see this anyway)* ***(78, widowed male, retired, no previous knee operations)***

In response to these questions, I would always stress that the consultant would not see the transcripts. In addition, I emphasised my social scientist background and informed them that I did not have the medical knowledge to answer their medical questions. I stated that it would be better if they discussed the issues with their GP or consultant.

Despite some of the informants believing I had a medical background, all acknowledged that I was a student. This 'student' role tended to aid rapport and gave the informants confidence to speak freely about their condition. For example, informants stated they were more than willing to discuss their experiences to someone who wanted to listen and were therefore eager to help:

*Mrs C: but it is nice talking to someone that does understand and wants to understand more, which helps me feel better about it.. it's been very nice .* ***(63, married female, retired, no previous TKR)***

Consequently, the informants described the interview as a positive experience, and spoke of the value of having the chance to talk about their problems and thoughts about the TKR and outcome:

*Mrs L: you have done me a power of good, helped me talking cos you bottle it up and you don't want to tell other people, they don't want to hear it.. but at least it brings it out.* ***(80, widowed female, retired, previous THR)***

## Summary of findings and future work

The aims of this study were to explore the experiences of those with severe OA undergoing a TKR. Within the literature a number of recurring themes have been identified in relation to chronic illness (uncertainty, stigma, biographical work and narrative reconstruction, sociology of the body, managing regimens, information, awareness and sharing, family relations, and coping mechanisms). This study verified that OA is a chronic condition, involving all of the themes cited above. For example, the informants described their OA in terms of a 'biographical disruption'. Although OA is universally considered a 'normal' process of ageing, the connotations and consequences of having a disability which emphasised the negative image of ageing (being dependent or a 'burden' on others) caused the informants distress. As a consequence, the informants felt stigmatised and felt embarrassed about their body image and therefore withdrew from activities or covered the pain and disability experienced. The symptoms experienced also caused what is termed 'trajectory uncertainty' where the unpredictability of symptoms led to uncertainty and fear of doing activities. The informants also underwent the process of managing regimens, gathering information and coping with their OA, in order to maintain a sense of control over their lives.

This study re-confirmed and elucidated findings which indicate potential barriers to utilisation of TKR. The patient's decision to seek treatment centred on the informant's perception that their 'normal' OA symptoms were sufficiently severe to warrant treatment, as well as accidental injury which required medical attention, and social sanctioning from friends and family. The decision of the medical 'gatekeeper' was also highlighted as important and informants believed that the GP's opinion of the severity of the knee OA and their attitudes about the outcome of conservative management and surgery, delayed referral. The decision of the surgeon to carry out the TKR was perceived to be driven according to the informant's age, weight, how loudly the individual shouted, and how much money there was in the system. Informants believed that pain and disability should be key factors on which to prioritise people for a TKR, as well [104]as specific factors related to the patient's circumstances, including the length and degree of suffering, whether there was a chance of getting back to work, whether the individuals had dependants, and whether the individual had paid their national insurance. This study reported only on what the patients thought happened in practice

rather than evidence of what actually happened. Future work is needed to confirm or refute whether there is evidence for the biases mentioned by the informants (such as age and obesity) that affect who is actually operated on. An important issue that this study had raised is the origin of the bias which results in a patient being referred or put on the waiting list or not. Future work is required to address these issues and explore the nature of patients', GPs' and consultants' decision-making processes.

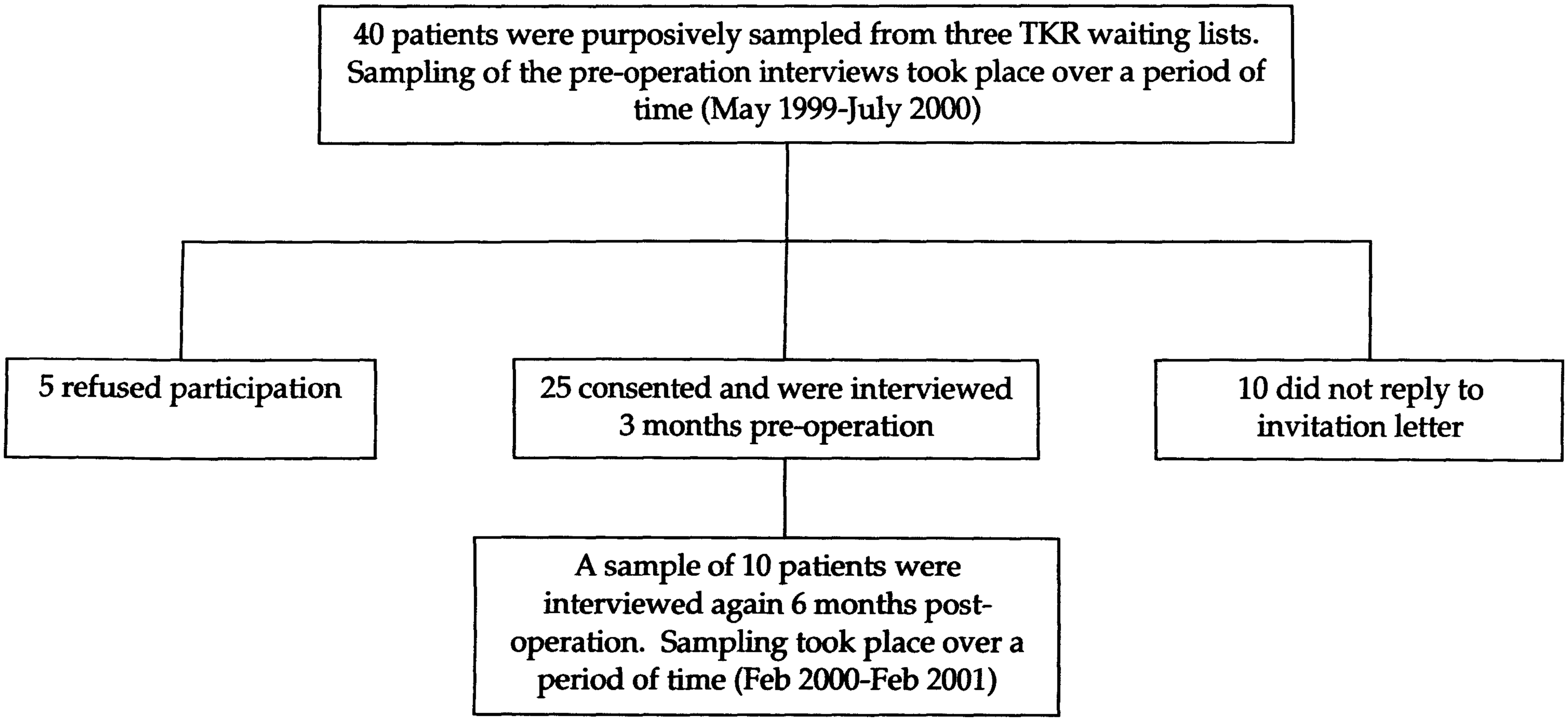
This study has made two original contributions. First, contrary to previous quantitative literature, it was found that patients experienced difficulty in articulating their expectations about the TKR at the pre-operation interview and preferred to describe their hopes and fears rather than give predictions about what would happen. It was also found that it was only after the experience of the operation that the informants were able to describe their expectations in light of what actually occurred in the hospital. This has important implications for research which suggests that satisfaction is influenced by the fulfilment of expectations. The fact that many realities are unanticipated means that individuals may not know what to expect. Therefore, expectations cannot be used as a starting place on which to base an assessment of the level of satisfaction. Continued efforts to measure expectations, especially using quantitative methods, may be of little value. A better construct may be to record the main hopes and fears of the patients and consider them in the context of their actual experiences and post facto rationalisations.

Second, the study showed that assessing the outcomes of TKR is complex. Individuals struggled to understand their outcome and often described their outcome in contradictory terms: they viewed the outcome of the TKR as positive despite the continued experience of pain and immobility. They presented both a 'public' expression of the outcome reflecting their socially desired view as a success, and a 'private' expression of the TKR outcome, reflecting the remaining pain and disability. The 'public' statement of the outcome from TKR may correspond to the favourable published results of TKR. However, the 'private' expression of the remaining pain and restriction of movement may not be captured with quantitative methods. Examination of the case studies demonstrated that these apparently contradictory accounts were consistent in the context of the informants' lives, and represented adaptation, rationalisation or accommodation to their changed health state. As a result of these explanations, they continued to consider the TKR with high regard.

Thus, previous assumptions that TKR is a highly effective procedure may need to be qualified by these findings. More sensitive assessments of outcome are needed to capture patients' experiences, which incorporate the process of reconceptualising outcome and take into account the context of the individual.

## APPENDIX I

***Flow chart outlining selection stages of purposive sampling***



# APPENDIX II

## *Consultant's covering letter*

Patient name and address

Date

Dear

You are currently on my waiting list for a knee replacement at [name of hospital] Hospital. I am writing to tell you about a research project that is taking place at the University of Bristol.

My colleagues there are interested in knee arthritis, the impact that knee problems have on day to day activities and about the experience of having a knee replacement, from the patients' perspective.

It is an important project which will enable us to understand the particular problems people encounter and their views on knee operations.

Enclosed is an information sheet for you to read. If you agree to take part, please return the reply slip in the envelope provided. You do not need to put a stamp on the envelope.

Any information that you give will be entirely confidential.

If you would like to discuss this with someone, please ring Gillian Woolhead on [telephone number].

Thank you very much for your help.

Yours sincerely,

Consultant Orthopaedic Surgeon

## *Patient Information Sheet and reply slip*

Dear

I am a PhD student at the University of Bristol and I am studying what patients think about knee arthritis and their experience of knee operations.

I am contacting you because you are on the waiting list for an operation at [name of hospital] Hospital. I would like to speak to you about your knee problems and the operation. If possible, I would like to visit you at your home, before and after your knee operation, to discuss with you your knee symptoms and their effect on your life. The main aims of the study are to explore people's views of knee arthritis, to look at the effect that knee problems have on day-to-day activities, and to know and understand what patients expect and want from knee operations.

I hope you would like to take part and I would be very grateful if you could complete the tear off slip below and post it back to me in the prepaid envelope enclosed.

You are under no obligation to take part and can refuse without giving any reason. If you choose not to take part or change your mind about taking part in the study, I can assure you that this will not affect your treatment in the future in any way.

If you have any questions you wish to ask, please feel free to contact me on [telephone number], or my supervisors Professor Paul Dieppe [telephone number] and Dr Jenny Donovan [telephone number]

I look forward to hearing from you.

Yours sincerely,

Gillian Woolhead

PhD Student

✂----------

**Name:**.....

**Please fill in your telephone number if you have one:**.....

*(Please tick the appropriate box)*

**I am happy for the researcher to contact me** ☐

**I would like more information** ☐

**I do not want to take part in this study** ☐

# APPENDIX III

## *Consent form*

Study Title: Patients' experience of arthritis and Total Knee Replacement

Have you read the Patient Information Sheet? YES/NO

Have you had an opportunity to ask questions and discuss this study? YES/NO

Have you received satisfactory answers to all your questions? YES/NO

Have you received enough information about the study? YES/NO

To whom have you spoken? .....

Do you understand that you are free to withdraw from the study:

At any time?

Without having to give a reason for withdrawing?

And without affecting your future medical care? YES/NO

Do you agree to take part in this study? YES/NO

Signed ..... Date .....

Name (in block capitals) .....

Signed (Researcher) ..... Date .....

# APPENDIX IV

## *Interview guide (pre-operation)*

**Experience of disease onset and action taken**

How long have you had knee problems?

Do you have any ideas about the cause?

Can you describe the problem?

Can you describe a typical day?

What are you most frustrated by?

Can you describe the pain? Is it different from night pain?

If you were pain free, what would you be doing now?

**Impact of illness and disablement on daily life**

Does your knee problem stop you doing anything you would like to do?

Has your knee problem changed your life in any way?

Can you tell me the last time you remember being in terrible pain?

How do you get around doing things.. do you avoid situations or not?

Does your knee stop you doing anything you would like to do

**Contacts with health and social services**

When did you first see your GP about your knee?

How long was it before you got an appointment at the hospital?

Do you take tablets for your knee?

Have you ever tried physiotherapy, or alternative medicines

How did you first come to see an orthopaedic surgeon for your knee problem?

**Extent of social support**

Do you know anyone else with your sort of problem?

Who was the first person to suggest that you should consider having a knee replacement?

Have you recommended a knee replacement to anyone else?

How did you decide to have the operation?

**Attitudes towards future**

What is the main symptom you want to be relieved?

What do you expect the surgery will do for you?

What are you hoping for?

What do you see yourself doing in 12 months time?

What do you think will happen in the operation/ what will the surgeon do?

How long do you think it will take to recover from the operation?

If you could choose between being more mobile but with pain or having less pain but not mobile, which would you choose?

Have you ever had any operations before? Can you tell me about them?

**Information about arthritis**

How do you think arthritis is perceived in society?

Do you have any information about your problem?

Do you think arthritis is an illness?

## *Interview guide (post-operation)*

**Experience of operation and hospital**

What has happened to you since I last spoke to you?

Describe how you felt before the operation?

Before the operation was performed, did they explain the after effects and recovery?

What happened on the pre-assessment/ward/recovery?

Can you tell me about the operation and your hospital stay?

If I had spoken to you at I month after the operation/2 month etc what would you have told me?

What were you feeling like.. what were your emotions?

How did you feel about a part of your body being replaced?

**Impact on daily activities**

How are you feeling at the moment?

How are you managing your daily activities?

Do you have any help with your household jobs?

Do you have any special gadgets in the house to help you?

**Expectations**

What did you expect before the operation?

Has this operation lived up to your expectations?

Do you think your expectations have been met?

**Satisfaction with treatment**

How do you feel now compared to before the operation?

Can you do things now that you couldn't do before the operation?

What is the main symptom, if any, that has been relieved?

If you had to do it all over again, would you have your knee replaced?

How would you rate your overall satisfaction with the results of your knee operation?

Would you recommend a knee replacement to anyone else?

# APPENDIX V

## *Post-operation request for interview*

Dear

I am a PhD student at the University of Bristol and I am interested in knee arthritis, the impact that knee problems have on day-to-day activities and the experience of having a knee replacement, from the patients' perspective.

You may remember I visited you at your home a few months before your total knee replacement, and I asked about your views of knee arthritis and the effect that it has on your life.

From my records it is approximately six months after your operation and I would be very grateful if you would agree to meet up again. This time I am interested in hearing about your experience of the operation, hospital and recovery process. I will phone you in the next week so we can arrange a suitable time.

If you do not wish to continue in this study you can refuse without giving any reason. If you have any questions you wish to ask before I visit you, please feel free to contact me on [telephone number].

This will be the last time I contact you. Any information that you give will be entirely confidential.

I look forward to seeing you again

Yours sincerely

Gillian Woolhead

PhD Research Student

# APPENDIX VI

## *Contact Summary Form*

Contact type:

Code:

Date:

Sex:

Age:

Written by:

What were the main issues or themes that struck you in this contact?

Summarise the information you got (or failed to get) on each of the target questions you had for this contact.

Anything else that struck you as salient, interesting, illuminating or important in this contact?

What new (or remaining) target questions do you have in considering the next contact with this site

# APPENDIX VII

*Characteristics of interviews with pre-operation informants*

| Patient ID | Place of interview | Comments on setting | Approx. length of interview | Comments on interview |
|---|---|---|---|---|
| Mrs A | Informant's home | Comfortable, husband present | 1 hour 30 minutes | The informant was nervous filling in the questionnaires but relaxed when the interview progressed. Her husband tended to talk about his medical problems as well. |
| Mrs B | Informant's home | Cold room, some background noise | 1 hour | The informant initially appeared nervous but relaxed during the interview. She was not very articulate about her expectations of the TKR. |
| Mrs C | Informant's home | Cold room, husband present | 1 hour 30 minutes | This was an interesting interview. The informant was nervous throughout the interview but gave some interesting views on her reasons for having a TKR and her phobia of doctors and hospitals. |
| Miss D | Informant's home | Comfortable, some background noise, one interruption | 1 hour | The informant was articulate and was happy to talk about most issues. |
| Mrs E | Informant's home | Hot room, background noise | 1 hour 30 minutes | This was an excellent interview. The informant was very articulate and gave clear and considered answers to questions. |
| Mrs F | Informant's home | Comfortable, husband present | 2 hours 15 minutes | This was a good interview. The informant was eager to talk about her OA but tended to concentrate on doctor/patient communication issues. |
| Mrs G | Informant's home | Comfortable, husband present | 1 hour | This informant had RA as opposed to OA and there were some interesting views on the topics. This informant can be used as a "negative" case. |
| Mrs H | Informant's home | Comfortable, husband present | 1 hour 10 minutes | The informant was relaxed and discussed most of the issues. |

Characteristics of interviews with pre-operation informants (cont'd)

| Patient ID | Place of interview | Comments on setting | Approx. length of interview | Comments on interview |
|---|---|---|---|---|
| Mrs I | Informant's home, retirement house | Comfortable | 2 hours | The informant talked a lot during this interview and gave many stories to describe her OA. |
| Mrs J | Informant's home | Hot room | 1 hour 15 minutes | This interview went well and the informant was happy to talk about her past and future TKRs. |
| Mrs K | Informant's home | Comfortable, husband present | 2 hours 30 minutes | This interview went well and rapport was easily established. The informant tended to concentrate on issues of waiting list times and the barriers encountered. The interview was cut short by the informant as she had another appointment. |
| Mrs L | Informant's home | Comfortable, one interruption | 1 hour 30 minutes | The informant initially appeared quite nervous but relaxed during the interview. She got very upset about her recently deceased husband and said she was very lonely. |
| Mrs M | Informant's home | Comfortable | 1 hour 40 minutes | The interview went well but the informant found some questions difficult to answer. |
| Mrs N | Informant's home | Comfortable, one interruption | 2 hours | The informant was very relaxed and was happy to talk about her views, although she did get confused about her different hospital appointments. |
| Mr O | Informant's home | Comfortable, one interruption | 1 hour 15 minutes | This interview went well. The informant was articulate and thoughtful and talked in detail his views on the indications to TKR. |
| Mr P | Informant's home | Comfortable | 2 hours | The informant appeared nervous during the interview and at one point got upset about his recently deceased father. |
| Mr Q | Informant's home | Comfortable, wife present | 1 hour 15 minutes | The informant was relaxed and attempted to make many jokes during the interview. His wife tended to interrupt when he was speaking. |

## Characteristics of interviews with pre-operation informants

| Patient ID | Place of interview | Comments on setting | Approx. length of interview | Comments on interview |
|---|---|---|---|---|
| Mr R | Informant's home | Comfortable, some background noise, one interruption | 1 hour 15 minutes | The informant was at ease during the interview and was happy to talk about his knee OA. He subsequently withdrew from the study and postponed his TKR to a later date. |
| Mr S | Informant's home | Comfortable, wife present | 2 hours 30 minutes | This was a very good interview. The informant was forthright and vocal about all issues. He gave an interesting account on why he thought the TKR would fail. |
| Mr T | Informant's home | Comfortable, one interruption | 1 hour 30 minutes | The informant was relaxed and happy to talk about all issues. He found the questionnaires difficult to complete. |
| Mr U | Informant's home | Comfortable, some background noise, two interruptions, wife present | 2 hours 20 minutes | The informant initially appeared out of breath but soon relaxed during the interview. It was an interesting interview as the informant said that he did not want the TKR. |
| Mr V | Informant's home | Comfortable, wife present | 1 hour 5 minutes | This was a difficult interview as the informant appeared reluctant to talk about his OA. His wife did most of the talking. |
| Mr W | Informant's home | Comfortable, one interruption | 2 hours 30 minutes | This was a difficult interview. The informant appeared to think I was from the hospital and kept asking for his operation date. |
| Mr X | Informant's home | Comfortable, wife present | 1 hour 10 minutes | The interview went well and the informant was happy to talk about the issues. This informant had just received notification of his operation date. |
| Mr Y | Informant's home | Comfortable | 1 hour 10 minutes | This informant was very matter of fact about his OA but gave considered answers to the questions. |

# APPENDIX VIII

*Characteristics of interviews with post-operation informants*

| Patient ID | Place of interview | Comments on setting | Approx. length of interview | Comments on interview |
|---|---|---|---|---|
| Mrs B | Informant's home | Comfortable | 1 hour 20 minutes | The informant talked mostly about the recovery of the operation, in particular her feelings towards blood transfusions. |
| Miss D | Informant's home | Comfortable | 1 hour | The informant articulated her experience of the TKR and the recovery very well. |
| Mrs E | Informant's home | Comfortable | 1 hour 10 minutes | The informant was disappointed with her outcome and did not expect the recovery to be so long. She complained about the hygiene of the hospital. |
| Mrs J | Informant's home | Hot room, one interruption | 1 hour | The interview went well and the informant was very welcoming. |
| Mrs L | Informant's house | Comfortable | 45 minutes | The informant seemed reluctant to talk about the operation. Although she was still experiencing pain, she thought the TKR was a success. |
| Mrs M | Informant's home | Comfortable | 1 hour 30 minutes | Tape recorder failed to tape interview all of the interview. Field notes were taken immediately after the interview. |
| Mr O | Informant's home | Comfortable, wife and 2 year old daughter present | 1 hour 5 minutes | The interview went well. The informant discussed his outcomes and expectations to the operation very well. |
| Mr P | Informant's house | Comfortable, one interruption | 2 hours 10 minutes | The informant talked in detail about the anaesthetic and was disappointed with the outcome. |
| Mr S | Informant's house | Comfortable | 1 hour 30 minutes | The informant was happy to discuss many of the issues but did tend to talk about other unrelated topics as well. |
| Mr T | Informant's house | Comfortable | 1 hour | The informant discussed the outcome of his TKR well but said he was scared about being in hospital. |

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